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An Internal Examination and Evaluation of the Nebraska Health and Human Services System Delivery of Personal Assistance Services (Final Report)

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Final Report

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Submitted to
Nebraska Health and Human Services System

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I. EXECUTIVE SUMMARY

In 2001, the Nebraska Health and Human Services System (HHSS) applied for and received a one-year, transitional Medicaid Infrastructure Grant, provided for by the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA). In 2002, HHSS applied for and received an additional three years of funding (through 2004). This combined funding allowed Nebraska to support research that examines how the opportunities for people with disabilities to engage in competitive work could be improved.

Personal assistance services[1] (PAS) are a currently underutilized, but in many cases, necessary work support for people with disabilities. With TWWIIA funding, HHSS determined that an internal examination and evaluation of PAS service delivery was a necessary first step in examining and improving utilization of PAS statewide. The focus of this report is state delivery of PAS. This project aimed to provide documentation of current service delivery, to highlight areas of strength, deficiency and inconsistency, and to make recommendations to HHSS with respect to how it could address these issues.

The University of Nebraska Public Policy Center (PPC) was contracted to conduct an internal examination and evaluation of HHSS's statewide and regional provision of personal assistance services by reviewing federal and state policy regulating provision of PAS; documenting the process of obtaining and maintaining PAS with respect to the following: access and referral, enrollment and eligibility, scope of services, management and organization, and quality assurance/grievance processes; identifying areas of consistency and variation between service delivery areas; gathering information about provision of PAS by Nebraska's licensed, certified home health agencies; gathering consumer perspectives and experiences with PAS in Nebraska; and developing recommendations to HHSS regarding how provision of PAS could be improved.

To accomplish this, the PPC utilized a variety of research methods. These include:

- Review of research reports, academic literature, federal and state regulations, policy analyses, and other documentation;
- Attendance at two national conferences on PAS ("Expanding Horizons for Persons with Support Needs – Growing PAS/PCS Programs, New Hampshire, August 2001; "The Persistence of Low Employment Rates for People with Disabilities: Causes and implications, Washington, D.C., October 2001);
- Participation in a national audio teleconference on PAS ("Consumer Directed Personal Assistance Services: New Models and Initiatives, September 2001);
- Preparation and review of queries submitted to the HHSS Research Division;
- Facilitation of HHSS Central Office AKey Informant@ meetings;
- In-depth telephone interviews with six HHSS Long Term Care Administrators and 11 HHSS local office supervisors and case managers;
- Development and analysis of a home health agency mail questionnaire; and
- Facilitation of a consumer focus group.

[1] Personal assistance services encompass the range of services also known as "Personal Care Services."

The results of these efforts lead the PPC to offer 11 recommendations that we believe will assist the state's efforts to improve utilization of PAS statewide:

Outreach and Awareness

- Improve **internal communication within HHSS about PAS as a work support** by utilizing existing HHSS communication strategies such as HHSS employee newsletters, other employee communications, and listserv email messages.

- Develop and distribute **PAS informational materials for outreach beyond HHSS** through consumer service and advocacy organizations, including the League of Human Dignity and the League's Statewide Consumer Network, as well as medical centers, rehabilitation centers, community centers, advocacy groups, and educational facilities.

Case Management

- Develop and incorporate **PAS approval and management training** for new and existing HHSS employees into other training activities.

- Create a HHSS communications task force consisting of HHSS Central Office administrators, Long Term Care administrators, local office supervisors and case managers to develop **a communications plan that will ensure efficient dissemination of changes to the regulations**.

Recruitment and Retention of Independent Providers (Personal Assistants)

- **Investigate the feasibility of a PAS brokerage system** to organize and employ independent providers and enable the provision of fringe benefits.

- Encourage personal assistants to take advantage of **direct deposit.**

- Encourage the development of **statewide provider databases**, which could potentially be accomplished by a subcontract or broker.

- Encourage other organizations to provide **personal assistance training** for independent providers to improve quality of care and to allow additional independent providers to claim the "trained" pay rate, perhaps affecting retention.

Quality Assurance

- Develop a **standardized quality assurance process** that includes provider performance reviews. We also recommend that **quality assurance be included in PAS training.**

- **Investigate consumer-directed service delivery** models that enable consumers to develop their own definitions of quality service and a plan for participating in quality assessment.

PAS Federal/State Policy Options

- Conduct **additional policy analysis**, which would **further detail the federal parameters for the Personal Care Option along with state policy.**

II. INTRODUCTION

...No American should have to live in a nursing home or state institution if that individual can live in a community with the right mix of affordable supports…

Donna Shalala
Secretary of Health and Human Services
July 28, 1999, National Conference of State Legislators

Background

In 2001, the Nebraska Health and Human Services System (HHSS) applied for and received a one-year, transitional Medicaid Infrastructure Grant, provided for by the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA). In 2002, HHSS applied for and received an additional three years of funding (through 2004). This combined funding allowed Nebraska to support research that examines how the opportunities for people with disabilities to engage in competitive work could be improved. Personal assistance services[2] (PAS) are a currently underutilized, but in many cases, necessary work support for people with disabilities. The focus of this report is state delivery of PAS.

Established in the 1960's as part of Medicare and Medicaid policy, PAS makes it possible for people with disabilities to choose whether they want to live in institutions (e.g., nursing homes) or to receive similar support from personal assistants while living in community-based, home-settings. Given the strong institutional bias toward institutionalization in federal and state policies (ILUR 1999), the disability rights movement considers PAS to be the "centerpiece" of an "alternative approach to long-term care that seeks to meet the specific needs of people with disabilities and their desires to live and participate actively in their communities" (ILUR 1999: 7).

James Charlton describes: "Personal assistance is the crucial support that can often mean the difference between independence and dependence for people with significant physical disabilities. Personal assistants (PAs) might help people with getting out of bed in the morning, personal hygiene, cooking or shopping, and cleaning up. PAs often do tasks that would take a person with a disability a long time to do, thereby wasting both time and energy" (1998: 1). Increasingly, PAS is considered a potentially valuable support for people with psychiatric disability as well (Deegan, 2001; Pita, Ellison, & Farkas, 2001).

Historically, disability has been considered a medical issue (ILUR 1999). The establishment and ongoing support of PAS programs signifies a shift in political thinking about disability from a medical model to a social model. According to Kenny Fries (2000: 1), the medical model defines disability as an impairment that, if possible, should be cured. "If incurable, the person with the disability was marginalized or institutionalized. According to the medical model, it is the impairment that is the barrier to equal participation in our society." He continues: "We need to look at disability, however, from a social model. This model views the societal barriers (physical and attitudinal) as the ones that systematically exclude us from the mix. The disability experience is not solely rooted in bodily impairment."

[2] Personal assistance services encompass the range of services also known as "Personal Care Services."

Personal assistance services are the support people with disabilities need to live independently. Importantly, PAS can break down the social barriers identified within the social model by making living independently accessible. Through independent living, people with disabilities participate more fully in the everyday lives of their communities. Independent living gives people the opportunity to participate in the religious, educational, economic and social institutions of community life (HSRI 1991). Significantly, independent living can also facilitate participation in competitive, integrative employment (Nosek 1990).

Nebraska's HHSS recognizes the importance of PAS in providing for the long-term care needs of people with disabilities. At the same time, it acknowledges that PAS may be an underutilized service in the state. With TWWIIA funding, HHSS determined that an internal examination and evaluation of PAS service delivery was a necessary first step in examining and improving utilization of PAS statewide. This project aimed to provide documentation of current service delivery, to highlight areas of strength, deficiency and inconsistency, and to make recommendations to HHSS with respect to how it could address these issues.

Research Questions

The University of Nebraska Public Policy Center (PPC) was contracted to conduct an internal examination and evaluation of HHSS's statewide and regional provision of personal assistance services by:

- Reviewing federal and state policy regulating provision of PAS;
- Documenting the process of obtaining and maintaining PAS with respect to the following: access and referral, enrollment and eligibility, scope of services, management and organization, and quality assurance/grievance processes;
- Identifying areas of consistency and variation between service delivery areas;
- Gathering information about provision of PAS by Nebraska's licensed, certified home health agencies;
- Gathering consumer perspectives and experiences with PAS in Nebraska; and
- Developing recommendations to HHSS regarding how provision of PAS could be improved.

Methodology and Data Sources

To accomplish this, the PPC utilized a variety of research methods. These include:

- Review of research reports, academic literature, federal and state regulations, policy analyses, and other documentation;
- Attendance at two national conferences on PAS ("Expanding Horizons for Persons with Support Needs – Growing PAS/PCS Programs, New Hampshire, August 2001; "The Persistence of Low Employment Rates for People with Disabilities: Causes and implications, Washington, D.C., October 2001);
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- In-depth telephone interviews with six HHSS Long Term Care Administrators and 11 HHSS local office supervisors and case managers;
- Development and analysis of a home health agency mail questionnaire; and

- Facilitation of a consumer focus group.

This report begins with a brief discussion of federal and state PAS and home health care policy. The remainder focuses on actual practice rather than policy. In Sections 4 and 5, based on key informant interviews with HHSS staff, we describe how the current delivery of PAS actually occurs statewide. Following that analysis, we present findings from a home health agency questionnaire and a consumer focus group. In the final section, we draw on federal and state policy as well as actual service delivery to present a series of policy recommendations and rationale. The recommendations link policy and practice.

III. OVERVIEW OF FEDERAL AND NEBRASKA POLICY

Introduction

Title XIX of the U.S. Social Security Act established federal guidelines for state Medicaid programs. Medicaid is an entitlement program that pays for medical care for low-income persons meeting the eligibility requirements. The Nebraska State Legislature established the Nebraska Medical Assistance Program (i.e., Nebraska Medicaid or NMAP) in Neb.Rev.Stat. '68-1018 in accordance with Title XIX federal guidelines. The Nebraska State Plan (State Plan) for Title XIX is a comprehensive, written commitment by the state to administer Nebraska Medicaid in accordance with federal requirements. The State Plan was approved by the Federal Department of Health and Human Services and is a basis for determining federal financial participation in the state program.

Across the U.S., independent providers, known as personal assistants,[3] provide PAS. In Nebraska, home health aides (i.e., employees of home health agencies) provide similar services and are often considered a second means to obtaining PAS. Home health care, a federally mandated service, and PAS, which is *not* federally mandated, are administered under different federal and state Medicaid regulations. Because Nebraska relies on both methods of service delivery, this report addresses both PAS and home health care, with emphasis on PAS.

Given that the focus of this research is improving opportunities (and/or removing barriers) for people with disabilities to participate in competitive, integrative employment, it is useful to compare the service delivery of PAS with that of home health care in the context of competitive work. Generally, PAS is likely the better option. When compared to PAS, home health care has limited usefulness for several reasons. First, it is a highly structured, mandatory program, leaving little flexibility for states.[4] Second, home health services must be “medically necessary” and authorized by a physician's order as part of a written plan of care. A registered nurse (RN) is required to supervise home health aides. Third, service delivery is limited to an individual’s residence.

On the other hand, the PAS Personal Care Option is not federally mandatory and states have considerably more flexibility to design the program. PAS also, according to federal rule, does not need a physician's order or RN oversight for provision. (Note: Nebraska state regulations, however, currently do require a physician’s order to receive PAS). Federal regulations (4480) demonstrate that PAS is notably less "medical" in nature than home health care coverage and it also allows elements of consumer direction in service provision. Moreover, federal regulations expanded the delivery of PAS to include non-residential settings, but did not make the same change for home health care. In order to use home health care, workers with disabilities may need to be eligible for both home health care and PAS. They may use PAS at work and home health at home.

Note: Italicized text indicates a direct quote from the Code of Federal Regulations (CFR), State Medicaid Manual or the Nebraska Health and Human Services Manual.

[3] Personal assistants are also known as personal care aides.

[4] States must offer home health for individuals over age 21 who are entitled to nursing care. States may extend their coverage to individuals under age 21 through EPSDT.

Federal PAS Regulations under the Personal Care Option

The Federal Regulations, outlined in the State Medicaid Manual, Part 4-Services, Section 4480 describe the PAS/Personal Care Option as:

> *Personal care services covered under a state's program, which may include a range of human assistance, provided to persons with disabilities and chronic conditions of all ages, which enables them to accomplish tasks that they would normally do for themselves if they did not have a disability. Assistance may be in the form of hands on assistance (actually performing a personal care task for a person) or cuing so that the person performs the task by him/her self. Such assistance most often relates to performance of activities of daily living (ADLs) and instrumental activities of daily living (IADLs). ADL's include eating, bathing, dressing, toileting, transferring and maintaining continence. IADL's capture more complex life activities and include personal hygiene, light housework, laundry and meal preparation, transportation, grocery shopping, using the telephone, medication management and money management. Skilled services that may be performed only by a health professional are not considered personal care services.*

PAS was originally intended to help consumers remain in their homes when they might otherwise have to be in a hospital or nursing facility. As stated in the Social Security Act (1905(a)(24)), "*PAS is an optional Medicaid benefit provided to individuals who are not inpatients or residents of a hospital, nursing facility, intermediate care facility for the mentally retarded, or institution for mental disease*." Consequently, initially, PAS could only be provided in home settings.

Effective November 11, 1997, however, the Center for Medicare and Medicaid Services (CMS)[5] published a final regulation in the Federal Register allowing states to broaden provision of PAS to include places "other than home," such as worksites.

Current federal regulations (4480 CFR) offer states choices within the following parameters. PAS must be:

- *Authorized for an individual by a physician in accordance with a plan of treatment or in accordance with a service plan approved by the state;*
- *Provided by a qualified individual who is not a member of the individual's family* (states choose who is considered a family member)*; and*
- *Furnished in a home or other location.*

Within the federal regulations for the Personal Care Option, states make the following choices (Gold 2001):

- Whether to require physician (or some other licensed person) approval or to utilize some other type of service plan;
- Their own scope of services for PAS, which can be more limited in scope, but not more

[5] The Center for Medicare and Medicaid Services (CMS) was formerly the Health Care Financing Administration (HCFA).

expansive, than the federal definition;
- Who is included in the definition of family;
- Whether to provide PAS only in the home or also in other places;
- The number of hours of services allowed per day, week, or month;
- Whether services are limited to children, or available regardless of age; and
- The amount of consumer direction allowed in the program.

Nebraska's PAS Regulations under the Personal Care Option

Scope of Services

Nebraska Medicaid (471 NAC 1-002) covers "*personal care services*" when "*medically necessary and appropriate under the program guidelines and limitations*."

NMAP covers personal care services when ordered by the client's physician based on medical necessity. Personal care services are medically-oriented tasks related to a client's physical requirements (as opposed to house-keeping requirements). These services are offered to individuals who, due to illness or disability, need personal care assistance to remain in their home environments.

Medical necessity refers to *health care services and supplies, which are medically appropriate and:*

- *Necessary to meet the basic health needs of the client;*
- *Rendered in the most cost-efficient manner and type of setting appropriate for the delivery of the covered service;*
- *Consistent in type, frequency, duration of treatment with scientifically based guidelines of national medical, research, or health care coverage organizations or governmental agencies;*
- *Consistent with the diagnosis of the condition;*
- *Required for means other than convenience of the consumer or his or her physician;*
- *No more intrusive or restrictive than necessary to provide a proper balance of safety, effectiveness, and efficiency;*
- *Of demonstrated value; and*
- *No more intense level of service than can be safely provided* (471 NAC 1-002.02A).

Personal care services may include:

- *Basic personal care and grooming, including bathing, care of the hair, care of the nails (except for diabetic clients), help with dressing and ambulation, etc.;*
- *Assisting with bladder and/or bowel requirements (does not include catheter care), helping the client to and from the bathroom, or assisting the client with bed pan routines;*
- *Assisting the client with oral medication that is ordinarily self-administered, when ordered by the client's physician. This does not include pre-filling syringes for diabetics;*
- *Assistance with nutrition and compliance with special diet, including the preparation of meals for the client;*
- *Performing household services related to a medical need if essential to the client's health and comfort in his/her home. Examples include changing bed linens, rearranging furniture to*

enable the client to have mobility, laundering personal clothes & linens, etc.; [6] *and*

- *Accompanying the client to clinics or physician office visits, or on other trips to obtain medical diagnosis or treatment when the client is unable to travel alone*.

  Exception: Personal care services may be provided at a client's worksite when the client is engaged in competitive integrative employment, for example: assistance with toileting or eating a meal. Competitive integrative employment is defined as a working a minimum of 40 hours/month at minimum wage (471 NAC 15-002).

Nebraska Medicaid will not cover, as PAS, services that must be *performed by persons with higher levels of professional training*,[7] such as:

- *Insertion and care of any type of catheters;*
- *Irrigation of any body cavities;*
- *Application of dressings involving prescription medication and sterile techniques;*
- *Mild, moderate, or severe skin care;*
- *Giving of injections into veins, muscles, or skin;*
- *Filling of insulin syringes for diabetic client;*
- *Nail care for diabetic client;*
- *Administration of oral medication (as opposed to assisting with self-administered medication); and*
- *Administration of oxygen* (471 NAC 15-003).

Nebraska Medicaid covers, as PAS, services that are considered homemaker and/or chore services that only benefit the consumer and do not directly benefit other household members. This means that PAS do not include:

- *Cleaning of floor and furniture in areas not occupied by the client (i.e., cleaning of the entire home if the client occupies only one room);*
- *Laundry other than that used in the care of the client (i.e., laundering of clothing and bedding for the entire household);*
- *Shopping for groceries or household items other than items required specifically for the health and maintenance of the client. This does not prevent a personal care provider from shopping for items needed by the client, but also used by the rest of the household; and*
- *Preparation of meals for entire household* (471 NAC 15-003).

Approval Process

Local office staff shall obtain a physician's order (including diagnosis) for personal care aide services. The order must be renewed when the client's medical condition changes requiring and increase in services, or at least every six months. (471 NAC 15-006.03) When local office staff receive the physician verification, PAS is provided under the direction of a Personal Care Plan (Form MC-73).

[6] PAS do not include general housekeeping. General housekeeping are considered "chore" services and may be available under a Nebraska Medicaid Waiver.

[7] Nebraska's Nurse Practice Act may allow personal assistants to conduct skilled nursing services, but this is not reflected in state regulation manuals governing PAS service delivery.

Local office staff shall enter the instructions to the provider regarding the personal care tasks to be performed on Form MC-73 (see 471-000-95). The local office staff shall give one copy to the provider and keep one copy. Local office staff shall complete Form MC-73 initially before the provider begins services for the client; and whenever the client's conditions or needs change; or at least every six months (471 NAC 15-006.04).

In many instances, the client's needs require both personal care aide services and homemaker or chore services, which are furnished by the same provider. Local office staff shall assist the client and provider in coordinating the services (471 NAC 15-006.05).

PAS can be provided as an aide visit or as a block of service, (e.g., four continuous hours). While the federal regulations do not cap the number of hours of PAS a client may receive, HHSS generally limits PAS to 40 hours/week. HHSS Central Office[8] approval must be obtained for services in excess of 40 hours per week (471 NAC 15-004.03).

Eligibility

To receive PAS, a consumer must be eligible for Medicaid. Local office staff must obtain a physician's order (including diagnosis) for PAS and complete a Care Plan. The consumer's status must be renewed when the consumer's medical condition changes requiring an increase in services, or at least every six months. The physician's order becomes a permanent part of the consumer's case file.

Providers

A provider is any individual that supplies Medicaid goods or services under an approved provider agreement with HHSS. In Nebraska, under the Personal Care Option, consumers obtain personal assistant services through independent providers. Home health care is provided by home health aides.

1. Personal Assistants (i.e., independent providers)

According to the Nebraska Department of Health and Human Services Manual (471 NAC 15-004.02):

PAS must be provided only-

- *In the client's home. Exception: Personal care services may be provided at a clients worksite when the client is engaged in competitive integrative employment, for example: assistance with toileting or eating a meal. Competitive integrative employment is defined as working a minimum of 40 hours/month at minimum wage.*
- *By an individual who is age 19 or older;*
- *By an individual who is not a legally responsible relative (spouse or parent/stepparent of minor child);*
- *By an individual who is qualified to perform the services; or*

- *By an individual who is not engaged in or has an ongoing history of criminal activity that may be harmful or may endanger individuals for whom s/he provides services. This may*

[8] Central Office refers to HHSS's office in Lincoln, Nebraska.

> *include a substantiated listing as a perpetrator on the child and/or adult Central Registries of abuse and neglect.*

Local office staff interview independent providers applicants. During this pre-approval interview, the local office completes the Personal Care Aide Checklist (MC-84) (471-000-94) and checks the Abuse and Neglect Central Registries to determine if any substantiated reports of abuse or neglect by the provider-applicant exist. If there is a report of abuse or neglect, the applicant will not be approved.

When the provider-applicant passes the Abuse and Neglect Central Registries Check, he/she must complete the generic Medical Assistance Provider Agreement (Form MC-19) (400-000-90). Once approved, local office staff sends the completed Provider Agreement form, a copy of the license or certificate of aide training when applicable, and a copy of the checklist to the Medical Services Division at the HHSS Central Office for approval. When approved, Central Office staff assigns a unique provider number to the provider (471 NAC 15-006.02-02A).

2. Home Health Agencies

Home health agencies are not regulated under the Personal Care Option. Rather, home health agencies have been defined by the state (471 NAC 9-001.01) as:

> *Home health agency means a proprietary or nonproprietary agency or organization, or a part of an agency or organization that is licensed and meets the requirements for participation in Medicare or the Joint Commission on Accreditation of Healthcare Organization.*

Nebraska Medicaid (471 NAC 9-001.02) *covers home health agency services to assist consumers attain or retain their capacity for independence or self-care in the least restrictive environment by providing payment-*

- *For the most appropriate and cost effective medical care necessary to maintain rehabilitate, or improve the client's quality of life;*
- *To agencies who meet Medicare certification by the Nebraska Department of Health accredited by the Joint Commission on Accreditation of Healthcare Organization for home health agencies licensed/certified/accredited in other states; and*
- *For medical services provided to medically and categorically needy clients who are eligible for Nebraska Medicaid.*

Home health aides must be under the supervision of a licensed nurse and utilizing a treatment-plan established by a physician, which indicates the consumer's need. Further,

> *The home health agency shall maintain a clinical record that includes the plan of care signed by the physician responsible for the client's care. The attending physician and home health agency personnel review the total plan of treatment at least every 60 days. The home health agency shall maintain these records on all Nebraska Medicaid clients and make them readily available upon the Department's request.* (471 NAC 9-002.04)

Payment Process

Since July 1, 1996, HHSS has paid for PAS at the lower amount of: 1) the provider's submitted charge, or 2) the allowable amount in the Nebraska Medicaid Personal Care Aide Fee Schedule (471-000-515). HHSS has the authority to adjust the fee schedule to comply with any state or federal requirements. Rate increases occur on July 1 of each fiscal year.

The rule (471 NAC 3-000.01) is stated as follows:

HHSS must approve payment for medical care and services through Nebraska Medicaid funds. Claims are approved for payment when all of the following conditions are met:

- *The client was eligible for Nebraska Medicaid when the service was provided, or the service was provided during the period of retroactive eligibility;*
- *No more than 12 months have elapsed from the date of service when the claim is received by HHSS;* [9]
- *The medical care and services are within the guidelines of Nebraska Medicaid;*
- *The client's case record contains information to meet state requirements; and*
- *A provider agreement is on file with HHSS, as well as the certification and transmittal from the state licensing agency or the CMS Regional Office, when required.*

For payment to both home health agencies and independent providers, *there is an ongoing monitoring and post payment review process. During the review process, refunds can be requested if claims and/or services have not been provided in compliance with Nebraska Medicaid policies and procedures. If this happens, claims submitted after the review has been conducted could be placed as pending until the review is complete* (471 NAC 3-001.03).

1. Personal Assistants (i.e., independent providers)

Personal assistants use the Personal Care Aide Claim Form (Form MC-82) to bill for services provided to Nebraska Medicaid consumers.

In addition,

For payment purposes, a personal care aide is considered to be a "trained" aide when the provider has successfully completed a basic aide training course that has been approved by the Nebraska Department of Health, has passed the Nurse Aide Equivalency test, or is a licensed R.N. or L.P.N. and presents a copy of the certificate or license to the case manager (471 NAC 15-005.02). In FY 2001, "trained" aides received $8.00 per hour and "untrained" aides received $6.50 per hour. In FY 2001, of personal assistants enrolled in Nebraska Medicaid, 711 were "trained," 837 were "untrained," two were "unknown."[10]

2. Home Health Agencies

With respect to payment to home health agencies, Nebraska regulations (471 NAC 9-003.01)

[9] There are some exceptions to the payment process. HHSS may still make payment for claim items received more than 12 months after the date of service if the circumstances that delayed the submittal were beyond the provider's control (i.e., consumer's retroactive eligibility, providers eligibility, unusual Central Office delay, etc.). At any case, the determination is made at the discretion of HHSS.

[10] Source: HHS Finance and Support research staff

state:

Payment for all home health agency services must be authorized. The eligibility of the client must be verified by the home health agency. Medical Services Division or its designee may grant authorization of payment for home health agency services. Providers shall send requests for authorization to the Medical Services Division at the Central Office. To request authorization the home health agency shall submit Form HCFA-1450 (UB-92) and attach a copy of the physician's order and the home health agency's treatment plan. The home health agency shall attach this documentation to each claim submitted for payment. The treatment plan must include:

- *The client's name, address, case number, and date of birth;*
- *The dates of the period covered (not exceeding 60 days);*
- *The diagnosis;*
- *The type and frequency of services;*
- *The equipment and supplies needed;*
- *A brief, specific description of the client's needs and services provided; and*
- *Any other pertinent documentation that justifies the medical necessity of services.*

Quality Assurance/Grievance Process

The following participation standards cover not only PAS, but cover all services that are provided under Medicaid. For all programs administered under Nebraska Medicaid, including PAS and home health care, Nebraska prohibits agreements in which the safety of the consumer is at risk. To that end, the HHSS Director and designated staff must ensure that all HHSS programs are administered in accordance with the rules and regulations of HHSS, state statutes, and federal laws and regulations.

HHSS *may refuse to execute, or may cancel, a provider agreement with a provider when there is demonstrable good cause. Good cause is defined as, but is not limited to: 1) the provider does not meet the standards for participation required by the NMAP (Nebraska Medicaid Program) which are listed in the appropriate chapter of Titles 471, 480, and/or 482; for each type of service or 2) the provider, or an employee of the provider, has been excluded, sanctioned, or terminated from participation by Medicare or Medicaid in Nebraska or another state* (471 NAC 2-002).

No provider agreement will be issued or remain in effect if there is a conviction for, admission of, or substantial evidence of crimes against a child or vulnerable adult, crimes involving intentional bodily harm, crimes involving the illegal use of a controlled substance, or crimes involving moral turpitude on the part of the provider or any other household members. The provider and household members must not engage in, or have a history of, behavior injurious to or which may endanger the health or morals of the client (471 NAC 2-001.02A).

Nebraska has policies in place to protect every applicant and consumer enrolled in any program administered by HHSS. Therefore, each applicant or consumer of any program, including PAS, has the following rights (465 NAC 2-001):

- *To receive action on his/her application for benefits within 45 days;*
- *To have his/her information treated confidentially; (see 465 NAC 2-005);*

- *To receive adequate notice of any action affecting his/her application or case;*
- *To receive equal protection under the law. No person may be discriminated against on the basis of race, color, national origin, sex, age, handicap, religion, or political belief;*
- *To have program requirements and benefits fully explained;*
- *To receive assistance in the application process from a person of his/her choice;*
- *To be referred to other human service agencies;*
- *To apply for assistance (see 465 NAC 2-001.01); and*
- *To appeal to the HHSS Director for a fair hearing (see 465 NAC 2-001.02).*

Consumers or a group of individuals may contest decisions if they feel any of these rights have been violated through a hearing, a declaratory order, and/or negotiated rulemaking.

Nebraska's PAS Choices

As mentioned previously, states are not required to include the Personal Care Option as part of their Medicaid State Plans. It is not a mandatory service to be provided under Medicaid. Consequently, states have some flexibility in designing their PAS programs. Like other states, Nebraska made these decisions when designing its PAS program. Drawing from the information presented in the previous section and given the federal parameters, it is useful to outline what Nebraska's choices have been.

- Scope of services – Nebraska's scope of services remain medically-oriented.
- Physician approval – for a consumer to receive PAS in Nebraska, he/she must obtain (or HHS staff will obtain) physician authorization. The state could choose to eliminate this step, replacing physician involvement for another licensed professional or other entity in conjunction with a care plan.
- Family providers – in Nebraska, to be paid through Medicaid, a PAS provider cannot be a legally responsible relative (spouse or parent/stepparent of minor child) of the consumer. A provider can, however, be a sibling or adult child of the consumer.
- Location – Nebraska amended its State Plan to include PAS service delivery in competitive, integrative employment settings. PAS has always been available in the home.
- Service cap – Nebraska limits the number of hours a caseworker can approve for a consumer receiving PAS to 40 hours a week. Any additional hours must receive approval from Central Office. With Central Office approval, though, there is no limit to the number of hours that may be approved. Most states limit PAS by cost and/or hours.
- Age – In Nebraska, services are available to eligible consumers of any age.
- Consumer direction – Currently, Nebraska's program allows for some consumer direction. Consumers are involved in obtaining, training, and, if necessary, firing their personal assistants.

IV. ORGANIZATIONAL APPROACHES TO SERVICE DELIVERY

Introduction

Nebraska Medicaid is administered statewide by the Nebraska Health and Human Services System (HHSS).[11] Recent reorganization involved collapsing six service areas into three service areas (see Appendix B). At the time of this study, there were still six service areas. These six areas served as the geographical areas of focus for the study. Each service area is administered by a "service area administrator" and long-term care services are administered by "long-term care administrators." Each service area contains many local offices, which are managed by local office managers. Local offices house case managers (e.g., social service workers), case aides (i.e., support staff to case managers), and where applicable, resource development staff. Central administration staff (Central Office) and the Policy Cabinet, responsible for overseeing all operations of HHSS, are located in Lincoln, Nebraska.

Interviews with the six Long Term Care Administrators assigned to the six service delivery areas of HHSS indicate that the organization of PAS delivery differs by service area. While no service area administers PAS in the same way, two basic organizational models did emerge from the interview data. Some service areas reflect a greater degree of centralization, while other service areas are more decentralized.

In four service areas, service delivery tends to be de-centralized as PAS is available through any front line case manager. Generally speaking, to obtain services, a consumer who is interested in obtaining PAS must contact his/her case manager and communicate his/her interest in PAS. The case manager verifies the intake information, does the billing, utilizes resource development staff for provider referrals, and monitors the case. In the other two service areas, PAS is authorized by one person, a medically trained (i.e., nurse) Health and Human Services Program Specialist. In these cases, case managers do not authorize PAS.

This centralized/decentralized distinction presents a useful framework for comparing the organization of the six service areas. The following sections provide greater detail regarding the organizational approach of each service delivery area.

Southwest Service Delivery Area

Between FY 2000 and FY 2001, the Southwest Service Area experienced a slight increase in the number of PAS recipients (19.7% increase) and payments (10.9% increase).[12] In July 1999, the area served 61 people ($233,535 in payments). In July 2000, the number served increased to 73 ($259,104 in payments). There are six local offices in the Southwest Service Delivery Area that manage PAS cases. The offices are located in North Platte, Lexington, McCook, Imperial, Ogalalla, and Cozad.[13] In each office, a local supervisor oversees the provision of PAS through case managers. In turn, a Long Term Care Administrator oversees all local offices in the service area. There are a total of 28 case managers and six local office supervisors who work with PAS cases in this service area.

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[11] Nebraska Medicaid is administered by the Nebraska Department of Health and Human Services Finance and Support (HHS Finance and Support), a division of the Nebraska Health and Human Services System.

[12] See Appendix C. Persons Receiving Personal Care Services by HHSS Service Areas, FY 2000 and FY 2001.

[13] The Cozad office closed in mid-January 2002.

Some local offices in this service area have designated an individual case manager to specialize in PAS. This occurs when a local office receives a sufficient number of PAS cases to fill a case manager's caseload. In smaller offices like Imperial, all of the case managers work with PAS cases because there are not a sufficient number of PAS cases to fill a caseload.

Western Service Delivery Area

Between FY 2000 and FY 2001, the Western Service Area experienced a slight increase in the number of PAS recipients (5.6% increase) and payments (4.8% increase).[14] In July 1999, the area served 124 people ($584,435 in payments). In July 2000, the number served increased to 131 ($612,295 in payments). There are seven local offices in the Western Service Delivery Area. These offices are located in Alliance, Bridgeport, Chadron, Gering, Kimball, Rushville, and Sidney. With the exception of the Kimball office, they all currently handle PAS cases. There are 20 case managers, ten resource developers and four local office supervisors involved in the provision of PAS.

In this service area, case managers authorize PAS while resource developers facilitate the enrollment process for service providers.

Central Service Delivery Area

Between FY 2000 and FY 2001, the Central Service Area experienced a slight decrease in the number of PAS recipients (8.7% decrease) and payments (5.8% decrease).[15] In July 1999, the area served 277 people ($1,029,457 in payments). In July 2000, the number served decreased to 253 ($970,094 in payments). There are seven local offices in the Central Service Delivery Area that authorize PAS. There are 33 case managers, five resource developers, and six local office supervisors involved in the provision of PAS.

Similar to the Western Service Area, in five of the seven local offices in this service area, case managers handle their own PAS cases and find providers through resource development staff. Resource developers maintain lists of potential PAS providers who are approved to provide PAS and the hours that they are available to provide care. Resource developers are responsible for maintaining this list as well as other non-PAS related lists for case managers (e.g., available foster homes).

In the Hastings and Grand Island offices, case managers are the initial contact for consumers interested in PAS, but case managers refer these requests to either support staff or resource development staff for case management. In Hastings, the PAS cases are handed over to support staff. In Grand Island, the PAS cases are handed over to resource development. In all cases, case managers oversee and are ultimately responsible for case management.

[14] See Appendix C. Persons Receiving Personal Care Services by HHSS Service Areas, FY 2000 and FY 2001.
[15] See Appendix C. Persons Receiving Personal Care Services by HHSS Service Areas, FY 2000 and FY 2001.

Eastern Service Delivery Area
Between FY 2000 and FY 2001, the Eastern Service Area experienced a slight increase in the number of PAS recipients (6.9% increase) and payments (2.6% increase).[16] In July 1999, the area served 363 people ($2,748,838 in payments). In July 2000, the number served increased to 388 ($2,821,136 in payments). The Eastern Service Area has four Omaha area offices that handle PAS. They are located on Lake Street, Pacific Street, in the Intake Building (South 42nd), and in the Sona Building. In addition to Omaha, the Eastern Service Area also includes several surrounding smaller counties.

In this service area, the PAS process is highly centralized. A Program Specialist reviews PAS requests, verifying information in the request, if necessary, through a doctor's definition of need. In addition, the Program Specialist trains providers how to do billing, conducts Abuse Registry checks and approves the number of hours of service. The case manager's only involvement in this process is during billing when he or she sends the bi-monthly billing statement to the Central Office in Lincoln for final approval. In some instances, support staff assists case managers in this process. In addition, PAS service delivery for the elderly is contracted out to the Eastern Nebraska Office on Aging. For this population, aging staff serve as case managers.

Southeast Service Delivery Area
Between FY 2000 and FY 2001, the Southeast Service Area experienced a moderate increase in the number of PAS recipients (32.9% increase) and payments (22.3% increase).[17] In July 1999, the area served 155 people ($759,533 in payments). In July 2000, the number served increased to 206 ($928,959 in payments). The Southeast Service Delivery Area follows a similar structure to that of the Eastern Service Delivery Area. There is one primary contact for most PAS cases. Case managers in this service area enter intake information for the case into the computer system, but do not conduct case management (e.g., assessment, recruit providers) of PAS cases, instead the primary PAS contact serves as the case manager. Resource developers recruit providers and also check the Abuse Registry.

If a consumer requests a personal assistant through a private home health agency after hospitalization, the hospital contacts a home health agency and then the home health agency obtains the physicians' order and does the intake assessment. The home health agency actually does the assessment and documentation and obtains authorization from HHS for the services.

If a consumer requests an independent contractor provider, rather than a home health aide (from a home health agency) for PAS, then the PAS Program Specialist authorizes it. The Program Specialist also receives case referrals from Aid to the Aged Blind and Disabled (AABD) case managers, Temporary Aid to Needy Families (TANF) staff and others, particularly when a case is unusual and a medical determination needs to be made. The Program Specialist makes medical determinations and conducts site visits to determine if and how much skilled nursing may be needed.

[16] See Appendix C. Persons Receiving Personal Care Services by HHSS Service Areas, FY 2000 and FY 2001.
[17] See Appendix C. Persons Receiving Personal Care Services by HHSS Service Areas, FY 2000 and FY 2001.

Northern Service Delivery Area

Between FY 2000 and FY 2001, the Northern Service Area experienced a slight decrease in the number of PAS recipients (10.8% decrease) and payments (15.8% decrease).[18] In July 1999, the area served 148 people ($597,054 in payments). In July 2000, the number served decreased to 132 ($502,701 in payments). The Northern Service Delivery Area has 17 local offices that handle PAS. These offices are located in Fremont, Columbus, Tekamah, Westpoint, Dakota City, Macy, Wayne, Pender, Neligh, O'Neill, Ainsworth, Valentine, Norfolk, Center, Pierce, and Hartington. Ninety-seven case managers and five local office supervisors work with PAS.

This service area's approach to service delivery combines aspects of the centralized and decentralized models. Case managers are responsible for budgeting PAS hours, but do no other "case management" work. Resource developers primarily work with the Waiver Service Coordinators and may also work with the Social Services Block Grant. They also end up doing much of the approval for PAS.

[18] See Appendix C. Persons Receiving Personal Care Services by HHSS Service Areas, FY 2000 and FY 2001.

V. STATEWIDE AND SERVICE AREA DELIVERY OF PERSONAL ASSISTANCE SERVICES

Introduction

This section is an analysis and summary of ten phone interviews with HHSS employees, which were conducted during January and February 2002. Phone interviews were conducted with four front line case managers and six supervisors. Two individuals – one local office supervisor and one case manager (selected by the office supervisor) – were selected from the Western, Northern, Southwest and Central Service Delivery Areas. The supervisor and case manager interviewed work in the same local office. In addition, one HHS staff person working with PAS was selected from the Eastern Service Delivery Area and another was selected from the Southeast Service Delivery Area.

Due to the reorganization of HHSS effective March 1, 2002, the Eastern Service Delivery Area and the Southeast Service Delivery Area were in the midst of making significant changes to their PAS service delivery methods. The primary analysis presented for the Southeast Service Delivery area represents the process prior to the reorganization. To understand some of the impacts of the new organizational structure, an additional interview was completed to gather information reflecting service provision in that area after March 1, 2002. These comments are noted in italics.

The interviews were designed to gather information regarding the process of obtaining and maintaining PAS in each of the six HHSS Service Delivery Areas. Due to the small number of interviews and the fact that only one local office in each service area was sampled, the information presented here should not be considered exhaustive, rather indicative of the perceptions of the various interviewees *as has been communicated to us*. In a sense, we are mere reporters.

The interview data are organized and presented as the following components of the service delivery process: access and referral, enrollment and eligibility, scope of service, management and organization, and quality assurance/grievance processes. Analysis includes identification of consistency and variation between service delivery areas. Data are presented as a summary, with any exceptions of particular service areas highlighted.

Access and Referral

1. How do consumers find out about PAS?

Consumers access PAS in several ways. Most commonly, consumers learn about personal assistance through a doctor's referral, word-of-mouth from peers or family, or from a third party organization (e.g., the League of Human Dignity, Area Agencies on Aging). Consumers reported being most likely to learn about PAS through one or a combination of the above methods and not from a case manager (see Consumer Focus Group section).

This is not to say that case managers never refer consumers to PAS; just that case managers are not the primary method of referral. Case manager referral is most likely to occur if a consumer is in need of PAS at the time of the initial screening for Medicaid, and the case manager is knowledgeable about PAS. In the Eastern Service Area, referrals for PAS primarily come from

individuals in the medical community (i.e., doctor, hospital social worker). In the Central Service Area, referrals for PAS come from the medical community and Area Agencies on Aging. In the Southwest Service Area, referrals for PAS come from the medical community as well as from personal assistants themselves.

2. Once a consumer is approved, how is he/she matched to a provider?

The process of locating providers varies greatly between service delivery areas. The following methods are being used throughout Nebraska: 1) Consumers recruit their own providers, 2) HHS staff use a Shared Database/Excel Spreadsheet to locate providers, 3) HHS resource development staff recruit and screen potential providers.

Specifically, the Central Service Area utilizes a shared computerized database of approved and available providers (by county), which is updated by HHS staff. In this service area, HHS is responsible for locating providers. In the Western Service Area, HHS is also responsible for locating providers. HHS maintains a provider list. In the Southwest Service Area, HHS is also responsible for locating providers. HHS maintains a local office bulletin board of names of potential providers. Quarterly notices are sent to employees, which include an updated list of available providers. In the Northern Service Area, there is no formal list of providers. HHS does not actively recruit providers. Consumers are responsible for locating their own providers. (Note: A list of Chore Providers is maintained and sometimes referrals are made to chore providers to determine their interest in providing PAS.) In the Eastern Service Area, HHS maintains an unofficial list of providers interested in employment. The list is not comprehensive, the providers are not pre-approved, and the providers may or may not be currently available.

Enrollment/Eligibility

1. How often do case managers work with cases involving PAS?

Case managers generally work with between 170-200 cases[19] at one time. Of these, less than 25% involve PAS and this varies by service area. Some case managers do not work with PAS at all. Low PAS enrollment has been attributed to higher reliance on other programs, or the traditional use of unpaid family members or friends in small communities for personal assistance. Interviewees expect that the need for PAS will increase as the population ages.

Specifically, in the Central Area, all case managers have the potential to handle PAS cases. Generally, a case aide is responsible for recruiting providers as they are needed. However, some offices do not have case aides, thus the case manager is responsible for all of the paperwork, including both the provider and consumer enrollment and eligibility. Western Service Area caseloads are slightly above average (approximately 200 cases). In the Southwestern Area, the enrollment for PAS was relatively low. PAS cases are not handled on a daily basis, and not all of the case managers have PAS cases on their caseloads. In this service area, however, resource developers play an active role in PAS recruitment and placement.

[19] HHS Finance and Support research staff have no current data to verify caseload size.

Interviewees from the Northern Area indicated that the Social Services Block Grant was the primary program utilized to cover services for persons with disabilities. The PAS program is used mainly to handle overflow needs and services that the Block Grant cannot cover. Primarily, PAS is used to cover the gap in hours a client still needs after obtaining the maximum Block Grant services.[20] Staff usually only handle PAS cases once every two weeks, when the billing process occurs.

The Eastern Area and Southeast Area are structured much differently. Due to their centralized service delivery structure, the program specialists handle most of the work in PAS. *Post March 1, 2002, the centralized model has been changed to a method of service delivery that now includes all case managers. Rather than referring the PAS cases over to a program specialist, each individual case manager will now handle all aspects of PAS service delivery.*

2. What is the age range of consumers who receive personal assistance?

Consumers may receive PAS from birth until death. State data indicate that, for FY 2001, of 1200 consumers, 28 (2.3%) were between the age of 0-17 years, 594 (49.5%) were between the ages of 18 to 64 years, and 578 (48.2%) were 65 years or older.[21] Basically, the consumers are split between the 18-64 age group and the 65 and over age group, which indicates a high proportion of elderly consumers.

However, according to interview data, in most service areas, the majority of consumers obtaining services are elderly people with disabilities. Enrollment of working age people with disabilities and children with disabilities was reportedly extremely low. An exception occurs in the Southeast Area where interviews suggest that the majority of individuals receiving PAS are adults. Specific data reported by interviewees indicated that in Lancaster County, of the total 112 individuals receiving PAS, only 35 (31.3%) were over age 65. Thus, 77 (68.8%) individuals are either children or of working age.

3. Approximately how many of these consumers are working?

The interviews revealed that it is extremely rare for a consumer who has a personal assistant to also be working. Only in the Central, Western and Southeast Service Areas have the interviews reflected any instance in which a consumer is working and receiving personal assistance. This may be in part because most of the consumers (excluding the Southeast Area) who are currently receiving personal assistance are elderly (see above). It is important to note that even the few instances staff mentioned may also include individuals enrolled in training and sheltered work programs – not integrated, competitive employment, further reducing the number of independent workers.

4. Do you know of any consumers on your caseload who receive personal assistance services who are interested in going to work?

In all service delivery areas, no case managers interviewed believed they knew of anyone on their caseloads who would want to begin work.

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[20] Medicaid PAS may be the better option for workers with disabilities. The income cap for eligibility for the Social Services Block Grant (SSBG) is lower than that for PAS. Workers with disabilities are likely to earn over the SSBG income cap, thus losing eligibility for the program. In addition, Medicaid PAS generates a federal match dollar, but SSBG does not.

[21] Data prepared by HHS Finance and Support research staff.

5. How do you determine a consumer's need for personal assistance services?
Interviews with supervisors and case managers indicated that PAS in Nebraska is based on medical necessity and physician referral.

In the Central Service Area, consumers are responsible for recognizing their need for PAS and then contacting their case manager. Often, a relative or neighbor may suggest PAS to a consumer. In this service area, case managers are in close contact with the members of the medical community; therefore, a physician may contact a case manager on behalf of a consumer needing personal assistance. Case managers must reassess the case every six months. Since PAS must be ordered by a physician, every six months, case managers send out a form to the consumer's physician that gives an overview of the personal assistance program and then asks the physician if the consumer is still eligible for the program.

In the Western Service Area, staff also confirmed the medical basis for personal assistance. Medical need is usually identified through a personal interview with case manager, a phone call with the family, or phone call with the physician. In the Southwestern Service Area, need for personal assistance is based on medical need as stated by a physician. In the Northern Service Area, it was reported that the medical community is well aware of the personal assistance program. Approval for personal assistance is dictated solely by a physician's orders and HHSS Central office. Assessment may be done during a consumer's initial application for Medicaid. In addition, home health nurses often recommend the program after rehabilitation visits have ended.

In the Eastern Service Area, physician verification is also required. The case manager may also do an assessment at the time a consumer requests PAS. In the Southeastern Area need is also initially determined by physician verification. Prior to March 1, 2001, verification was followed up by a home visit from program personnel to determine medical needs of the consumer. A qualified program specialist determined hours. *Post March 1, 2002, the case manager is charged with assessing need, and no home visits will be conducted.*

6. What steps does a consumer have to follow to get approved for personal assistance?
All interviewees acknowledged that consumers must first be eligible for Medicaid before they can receive PAS. After a consumer contacts his/her case manager to determine initial eligibility, then he/she obtains his/her physician's authorization. Then the case manager and consumer complete a Personal Care Plan. The Care Plan identifies personal assistance needs, and determines how and when they should be addressed during each visit. Some case managers reported discomfort with the medical knowledge they believe is required to complete this form. Because some case managers and their supervisors do not believe they have the qualifications to complete the Care Plan, it reportedly is often only partially completed. In addition, other case managers reported that when a physician completes the Care Plan, it focuses too narrowly on physical care, overlooking other significant personal assistance needs (e.g., transportation, laundry).

In the Central Service Area, attempts are made to bring the consumer, case manager, and personal assistant together to complete the Care Plan. However, this is rarely achieved due to lack of time. Home visits are not conducted to complete the Care Plan. Case managers and

consumers prepare the Care Plan and consumers explain their needs to their personal assistants. Uniquely, in this service area, case managers often approve more hours than the physician orders because they take into account the personal needs of the consumer as well as the defined medical needs. This is the only service area that procedurally allows the approval of more hours than the physician orders.

In the Western Area, consumers contact their case managers for PAS. In this service area, case managers take the responsibility for acquiring the physician's authorization. Case managers send or fax a form to the physician to determine if the consumer needs personal assistance and, if so, for how many hours. The Northern Service Area is the only other service area that requires case managers to actually obtain the physician's written note, usually consumers must obtain it.

A unique trait of PAS provision in the Western Area is the completion of an initial home visit. Case managers conduct home visits to determine and assess the consumer's environment to determine if PAS is an appropriate program. In some cases, case managers suggest the chore services program instead of (or in addition to) the PAS program, if that program would best meet the consumer's needs. If the case manager and consumer determine that there is a need for PAS, the consumer obtains the physician's verification and is then referred to the Resource Development Team to acquire a PAS provider.

In the Western Area, reportedly, the completion of a Care Plan is done irregularly. Some case managers will send the incomplete Care Plan form to the physician for him or her to complete. In other cases, a Care Plan is not being used at all by case managers. The interviews from this service area indicate that case managers have found that when they send the Care Plan to the physician, it is often not completed. Therefore, service hours are determined solely on the physician's order, rather than the assessment in conjunction with the order. In this service area, there are no instances in which a case manager approves more hours than the physician orders.

In the Southwestern Service Area, the consumer is responsible for obtaining his/her physician's referral. Once a referral is obtained, the consumer contacts his/her case manager or resource development staff at the local office to begin the process of enrollment. The case manager assesses the consumer's need, reviews the Care Plan with the provider, and makes sure the provider understands the requirements of the program. With the exception of the completion and review and this initial care plan, resource development staff are the primary contact for the provider.

In the Northern Service Area, the process is similar to the Western Service Area: Case managers obtain the initial referral from the physician for the consumer. In this service area, if the consumer disagrees with the hours the physician determines for PAS, the consumer must discuss it with him/her. At this point, the physician's referral is no longer the responsibility of the case manager.

In the Eastern Service Area, the consumer obtains the physician's referral, which must include a diagnosis. Case managers send the physician's referral and a provider request for approval to a program specialist. The program specialist makes an appointment with the consumer to do a clinical diagnosis and determine hours of PAS needed. This approach is not common in the state. Only the Eastern and Southeastern Areas have program specialists – HHS employees

qualified to do home assessments to determine and verify PAS hours. *After March 1, however, the Eastern and Southeastern Areas were decentralized as well, eliminating the program specialist role.*

7. **Who in the local office does the consumer contact?**

In most cases, consumers speak with a case manager to initially request PAS. However, in some of the smaller rural offices, case managers may not be available, requiring consumers to speak with case aides or resource developers for general questions and referral.

Scope of Services

1. **What are personal assistant services? What types of services are covered under personal assistance?**

HHS employees consider PAS to be those services provided by a personal assistant to enable the consumer to remain in the home and out of a nursing home. This definition of personal assistance is consistent with the direct care and assistance for an elderly individual or person with a disability with respect to feeding, dressing, laundry, bathing/showering, medications and dietary needs. None of the interviews referred to personal assistance related to competitive employment. The focus of personal assistance, according to HHS employees interviewed, is to keep the consumer out of a nursing home.

In several instances, HHS employees suggested that the distinction between chore services provided under the Social Services Block Grant and PAS was confusing for both HHS employees as well as providers.

2. **What is the maximum number of hours you can authorize for personal assistance services?**

Generally, across the state, HHS employees believe they can authorize 40 hours a week of PAS before gaining HHSS Central Office approval. This is consistent with state regulations.

In the Central Area, 50 hours/week of personal assistance are allowed. Supervisors require that special approval must come from the HHSS Central Office for requests greater than 50 hours. Case managers in this area mentioned a 56-hour maximum, without realizing that the 56-hour maximum applies only to home health care. Confusion exists between home health care hour requirements and PAS.

In the Southwest Area, case managers maintained that no more than 40 hours per seven-day period were allowed. If a consumer needs more than this, the case manager would speak with the consumer's family and a physician to see if the consumer should be placed in a nursing home. The supervisor in this area maintained that if a request for more than 40 hours is made, the request must go to HHSS Central Office for approval. The supervisor did not indicate that a request for over 40 hours means that the consumer may need to be placed in a nursing home.

3. What number of hours is typically authorized?

On average, between 20 and 40 hours/week of personal assistance is authorized. There is a wide variation in the number of hours service areas authorize. It is unlikely that need for PAS is higher in some service areas, but rather other factors contribute to this discrepancy.

Central Service Area	40 hours (weekly)
Western Service Area	25-30 hours (weekly)
Southwest Service Area	20-40 hours (weekly) (in addition to the 60 hours/month authorized through the Social Services Block Grant)
Northern Service Area	N/A
Eastern Service Area	28 hours (weekly)
Southeast Service Area	28 hours (weekly)

4. How are providers notified of the hours and services for which the consumer is approved?

All service delivery areas are aware of the Care Plan to document the hours and services that the personal assistant must provide for the consumer. The Care Plan is generally completed and mailed to the provider, the provider then signs the form, agrees to the stated responsibilities for the consumer, and then mails the form back to the local office. Ideally, this process involves a joint meeting with consumer, provider, and case manager, but most often a joint meeting does not occur. Instead, the Care Plan is handled through the mail. If there are changes to be made to the Care Plan during the assignment, the changes are again made in writing and business is completed by mail.

In the Western Service Area, care plans are not always completed. Staff attributed this to confusion about the form and/or who is responsible for completing it.

5. What other information is given to the provider by the local office?

None of the local offices send out additional information to the provider. However, a packet of information including 471 Manual regulations and program guidelines, with the provider identification number and Care Plan are all sent from the HHSS Central Office to the provider once he/she is approved as a provider. The major difference between service areas is the availability of technical assistance for providers if they have questions or need assistance/clarification with the documents. Some offices assign the resource development staff the responsibility of helping providers understand their responsibilities, and other areas rely on case aides or request that providers call a case manager only if they have questions.

In the Central Service Area, case aides review the major points of the PAS contract sent from the HHSS Central Office with new personal assistants. All other information is provided through the mail. In the Western Service Area, providers are in close contact with the resource development staff for clarification. In the Southwestern Service Area, the resource development staff reviews billing and time sheet procedures with providers.

6. **On average, how long does it take after a consumer is approved before he/she begins to receive services?**

According to the interviews, the timing of service provision depends on the current status of the provider. If the personal assistant is already approved and in the HHSS system as a provider, services can usually begin immediately. If the provider is not currently pre-approved, the case manager will begin the approval process while also allowing service provision to begin. Once the provider is approved, the contract is often backdated, within reason, to the date services began.

In the Central Area, services can begin immediately if the consumer has already obtained a physician's statement and the provider is pre-approved. If the provider is new, the process can take up to two weeks. However, the Central Area allows the payments to go back to the date the contract was signed, if the provider is approved by the HHSS Central Office. If the provider was not approved, but has been providing services in the meantime, he/she cannot paid for that work. In the Western Area, if the provider is already approved, it takes one to two days before services can begin. If the provider is new, it can take a week to ten days. The resource development staff will try to place a pre-approved home health aide in the home until another provider is approved.

Decision Hierarchy/Management

1. **Who submits billings for payments to personal assistants?**

All offices require the providers to submit their billing payments to the local office. A HHS employee submits the billing request to the HHSS Central Office for payment. In all service delivery areas, case managers are responsible for verifying that the hours claimed for payment are within the boundaries of the services that have been approved for payment. The case manager always maintains responsibility for this aspect of the process.

According to the HHSS Central Office, the average length of time between receipt of the MC-82 (payment claim) form by Central Office and receipt of payment by the provider is generally ten days. The personal assistants turn paperwork in at the local office. The local office worker authorizes payment and sends the payment claim to Medicaid Claims Department. Over the weekend, a total of all Medicaid monies due (of which PAS is a part) are given back to claims processing and claims processing issues checks on Tuesday and they are mailed on Wednesday. Personal assistants may receive their paychecks either in paper form or through electronic deposit.

In the Southwest Area, resource development staff are responsible for signing the billing and sending it to Central Office. The Central Area has structured a system of prioritization for PAS billing. All PAS billing has a three-day turnaround. If a case manager is gone, the coverage team is aware that a PAS billing is earmarked as a priority item. The Central Area designed this system as a way of supporting its provider pool. Quick turnaround in payment is one way they have worked to maintain providers.

2. **Do you feel comfortable making decisions and answering consumer questions about personal assistance services?**

Generally speaking, supervisors feel comfortable answering questions related to PAS. Many case managers, on the other hand, do not. Most case managers rely on the regulations for direction, but they feel the program and the manuals are outdated. One person commented: This is the "only program that is run based off of the judgment of other people's decisions and information" (i.e., physician). Some of the case managers interviewed do not feel sufficiently trained to conduct assessments or to know the program well enough to answer questions.

Because PAS is currently used relatively infrequently, case managers often refer to the regulations or a co-worker to determine the necessary steps needed to guide service provision.

3. **Where in the office is the regulations manual? Who is responsible for updating it?**

Several offices were unsure of the location of the hard copy manual, but most were aware the regulations manual is also available online.

In the Central Area, according to the supervisor, each case manager has his/her own 471 Manual. However, the case manager stated that the 471 Manual is shared with everyone in the office. Supervisors are responsible for updating the manuals. In the Western Area, the supervisor keeps one full set of manuals. In addition to this set, HHS staff refer to the online version. On a monthly basis, the supervisor updates the manuals.

In the Southwestern Area, the supervisor reported that the manual is kept with support staff, and there is only one 471 Manual in the office. The case manager reported that staff have their own copy. HHS employees are supposed to update their own manuals with the assistance of support staff. In the Northern Area, there is just one 471 Manual located in one office for several counties. Staff were not sure where it was, but thought it was located near the clerical staff. Both the case manager and supervisor reported that they were unsure where to locate the regulations, but they were sure there was only one copy. Clerical staff are responsible for updating it.

In the Eastern Area, a regulation manual is located at each desk. Clerical staff are responsible for updating it. In the Southeastern Area, regulations are most often referred to online. Employees are responsible for updating their own manuals.

4. **How do case managers find out about changes to the regulations?**

There is no standardized process in place to find out about changes to the manual. Each service area utilizes its own method for distributing information about regulatory changes. In one case, it was mentioned that medical providers often know the regulations as much as or more than HHS staff.

If there is a major policy change, in the Central Area, staff receive the changes via email and/or by Central Office Policy and Program Staff. The case manager interviewed noted, however, that there is not an identified process in place to find out about changes. In the Western Area, hard copies of all new material are sent to HHS employees. Case managers are not responsible for filing and updating their manuals because of the time it would take from their other responsibilities. Also, since the regulations are available online, several employees simply refer

to this system instead of updating their hard copies. In the Southwestern Area, there is no identified way of notifying employees about changes. In the Northern Area, clerical staff are responsible for distributing updates. Important changes are placed on the next monthly staff meeting agenda.

Quality Assurance

1. **How are providers screened during the enrollment/application process?**

There are various methods used to screen providers. Currently, the Central Registry Check, Protective Services Check, and the State and Local Law Enforcement Check are used. Each service area identifies specifically the methods it uses. A Central Registry Check is done in all circumstances. However, some of the other methods (i.e., law enforcement) may be handled differently by county or service area. Interviewees felt that PAS providers are currently not screened as thoroughly as providers of other programs. There is no designated employee to conduct screenings and the structure is different in each service area.

In the Central Area, local and state law enforcement checks are done only in the county where the provider is currently residing. However, if staff feel that there is reason for suspicion, they may check more counties. A case aide is responsible for doing this screening. In the Western Area, resource development staff conduct the screenings through Adult and Child Abuse Checks and criminal background checks. In the Southwestern Area, in addition to the Central Registry, if staff are aware that a provider is not a resident of Nebraska, he/she may also check a provider's background in their residency state. The "trained" status of the provider is also checked. Resource developers are responsible for screening providers. In the Northern Area, staff examines the Central Registry check and Protective Services Check and Licensing to see if the provider is eligible for the "trained" provider wage.

2. **If a personal assistant does not show up, what is the consumer told to do?**

Consumers are responsible for having their own back-up personal assistants. In almost all circumstances, the interviewees stated that the consumer should call HHS. However, only one service area (the Western Area) has a system set up to actually respond to such a problem. In most cases, the HHS employees stated that "no-shows" have not been an issue.

In the Western Area, a local office will take the responsibility of placing another personal assistant in the home if a provider does not show. The consumer is told to call HHS immediately. After regular business hours, there is an emergency number listed on the answering machine. Also, the local police can call Adult Protective Services who will contact an Administrator at HHS. Staff in this area reported that, because of the small town context, some consumers have the home numbers of their case managers as well.

3. **How do you know if a consumer is getting the services he/she needs? How do you know if a consumer's needs change?**

Across the board, the only way HHS employees determine if consumers are getting the PAS they need is by the consumer's signature on the billing request. The billing request requires personal assistants to list the services provided and the consumer's signature indicating that those services were completed.

Friends, family members, the provider, or consumers are responsible for notifying HHS if consumers are not getting services they need. For the most part, HHS takes a reactive approach to quality assurance in this program. Consumers also are responsible for notifying HHS if changes need to be made to their Care Plans.

In the Western Area, case managers conduct unannounced home visits on a periodic basis. In the Northern Area, case managers are required to do an evaluation every six months and get a new physician authorization to verify the need of services.

4. **How often and for what reason are home visits conducted by HHS employees?**

Home visitation policies are not standard across the state. Each service area, and perhaps each local office, has its own criteria for home visits.

In the Central Area, HHS employees very rarely conduct home visits. In some cases, they are done under the waiver program or done by the Area Agencies on Aging. The case manager interviewed stated that there had only been one home visit conducted in the last three years. In the Western Area, it is required that whenever PAS or Social Service Block Grant services are required, a home visit must be conducted. Then, a follow-up home visit must be conducted yearly thereafter. This requirement is unique to this service area. In the Southwestern Area, staff try to conduct one home visit a year. However, in rural areas, interviewees reported that traveling is difficult. In the Northern Area, the need for home visits is based on enrollment in other programs. If the consumer is in a program that requires a home visit, they will do so. If the program does not require a visit, none is conducted. The Eastern Area is unique. Home visits are conducted very frequently. Most of these visits are conducted at the initial assessment for PAS. About ten percent of the total home visits conducted in this area are done as "spot checks."

5. **How and what kind of training have you received related to personal assistance services?**

No HHS employee interviewed had been involved in any formal PAS training other than medical training they had obtained on their own. On-the-job training or shadowing of another case manager was the extent of most training. Several of the employees interviewed felt that they lacked the medical training necessary to know certain parts of the program. In the Northern Area, it was reported that Central Office provides a training once a year that includes some PAS. Sometimes staff are sent to this training.

Summary

Interviews with 11 HHS employees addressed the following components of service delivery: access and referral, enrollment and eligibility, scope of service, management and organization, quality assurance/grievance processes. The following are areas of consistency among service delivery areas:

- According to the interviews, HHS employees believe that PAS is designed to keep consumers out of nursing homes. While PAS supports qualified people of all ages, not many consumers who receive PAS are participating in competitive, integrative employment.
- Interviews confirmed that, in Nebraska, PAS is based on medical necessity and physician referral. In order for a consumer to be approved for PAS, consumers must first be

eligible for Medicaid. In addition, physician authorization must be obtained and a Care Plan must be completed.

- Consumers learn about PAS through a doctor's referral, from peers, family, or a third party organization. For a variety of reasons, case management referral does not appear to be a primary point of access.
- Once a consumer is approved, consumers may recruit their own providers or HHS employees may use a shared database or other list to locate potential providers for the consumer. After a consumer is approved for services and a provider is located, services may begin immediately if the provider is pre-approved.
- To assure quality service provision, Nebraska requires HHS employees to conduct a Central Registry Check on potential providers. However, there are minimal uniform statewide standards to ensure quality.
- Currently, all offices require providers to submit billings to the local office. An HHS employee reviews and submits the billing request to Central Office for payment.
- Generally speaking, supervisors and case managers rely on the regulations manual to administer the PAS program. Local offices determine how to make manuals available and how to communicate changes in regulations.

VI. HOME HEALTH AGENCY QUESTIONNAIRE

Purpose
To gather information about provision of Home Health Care services by Nebraska's licensed, certified home health agencies.

Methodology
In November 2001, with direction from HHS, the PPC developed a questionnaire for home health agencies. In December 2001, HHS mailed 65 cover letters and the questionnaires to licensed home health agencies. During January 2002, 40 home health agencies returned completed questionnaires to HHS or directly to the PPC. All completed surveys received by HHS were forwarded to the PPC for data entry and analysis.

Number of Medicaid Clients Served (n^{22}=40)
- On average, Home Health Agencies serve 23 Medicaid clients at any one time.
- The responses ranged from zero to 220, and are extremely dispersed (std dev 38.49).[23]

Availability of Services (n=40)
- Of the 40 agencies who returned completed surveys, 12 provide services 24 hours a day, seven days a week.
- In addition, 28 agencies provide services only during the day and 26 provide services only Monday through Friday.
- Twelve agencies provide weekend services.
- Nine agencies provide services early in morning and on holidays.
- Six agencies provide services in the evenings.
- Most (87.8%) agencies provide services to their entire service areas, but some (12.2%) reduce service availability to more remote areas. One agency responded: "The greater the distance, the more limited the services." Another agency reported that availability of weekend and holiday services depended on staff availability.

Billing (n=40)
- Most (n=25, 61.0%) home health agencies do NOT provide split-hour billing.[24] One agency reported a willingness to provide split-hour billing if it were requested.
- Most agencies bill by the hour (n=29, 70.7%) and/or by the visit (n=30, 73.2%).

Lag Time (n=39)
- Most (n=33, 84.6%) of agencies reported a lag time between service request and assignment of a home health aide of only one to two days.
- Five agencies (12.8%) reported a lag time of three to five days.
- Only one (2.6%) reported a lag time of over five days.
- Several agencies reported a reluctance to accept a new consumer unless staffing is available to meet those needs.

[22] n refers to the total number of responses per each question.
[23] Standard deviation is the most commonly used measure of dispersion.
[24] Split-hour billing refers to when Aides visit a client for a few hours in the morning and then return to that same client later in the day.

Payment

- The average pay reported by home health agencies is $9.27 per hour.
- The pay ranged from $7.00 to $16.00 per hour.

Employee Benefits

- Benefits depend to a great degree on the number of hours an Aide works and/or the length of time the Aide has been with the agency.
- 36 agencies (90.0%) reported providing Worker's Compensation to employees (n=40).
- 35 agencies (87.5%) reported providing vacation time to employees (n=40).
- 34 agencies (85.0%) reported providing health insurance and reimbursement for transportation costs to employees (n=40).
- 27 agencies (69.2%) reported providing unemployment insurance to employees (n=39).
- 27 agencies (67.5%) reported providing retirement benefits to employees (n=40).
- Other benefits listed by agencies include: flexible hours/self-scheduling (n=10), complete benefit package (n=6), good working environment/supportive working environment (n=5), employee perks (e.g., movie tickets, free merchandise, gift certificates, free lunch on occasion, gas coupons, discounts on cell phones, free pagers, Wooden Nickel programs/Gem Bucks) (n=5), employee recognition program/anniversary program (n=4), continuing education/tuition remission (n=4), regular raises and evaluations (n=3), referral bonuses (n=3), no weekends/holidays/evenings (n=3), pay differential for different shifts (n=2), short term disability/sick pay (n=2), employee stock purchase plan (n=2), additional types of insurance (n=1), holiday pay (n=1), hiring bonus (n=1), consistent clients (n=1), regular part time or full time status (n=1), credit union (n=1), weekly pay (n=1).

Turnover Rate (n=38)

- Most (n=33, 86.8%) agencies reported an employee turnover rate of between zero to 25%.
- Two (5.3%) agencies reported a turnover rate between 26%-50%.
- Two (5.3%) agencies reported a turnover rate between 51%-75%.
- One (2.6%) agency reported a turnover rate between 76%-100%.

Quality Assurance (n=40)

- Most (n=38, 95.0%) agencies reported using a consumer satisfaction survey to assess service quality.
- Most (n=37, 92.5%) agencies also reported using performance reviews to assess Aide performance.
- Most (n=34, 85.0%) agencies also reported using Aide background checks to assure quality service provision.
- In addition, several agencies reported using competency assessment/demonstrations, in services/training, various accreditations (e.g., OBQI, JACHO).

Consumer Grievance Process (open-ended question)

- Most agencies reported that consumers follow a grievance process that includes reporting to an Aide supervisor, which is followed by an investigation. The Aide will be investigated and attempts are made to work out differences. If differences are

irreconcilable, a new Aide may be assigned to the consumer. In some places, though, only one Aide is available, so if the consumer chooses not to receive services from that Aide, he/she will have to change agencies or find other care. In addition, eight agencies reported using the Medicare Home Health Agency Hotline (phone number). Twenty-two reported providing 24-hour access to management in the case of an emergency.

Expansion of Services (n=40)

- Most (n=28, 70.0%) agencies reported no effort to expand services in recent years.
- Some agencies reported expanding the services provided to include pediatric care and supplemental staffing to other agencies, adding private care home health aide services, hospice and community-based services.

There are a number of home health agencies in Nebraska that are under contract with HHSS to provide strictly non-medical, homemaker/home helper services through a Medicaid waiver program. The PPC interviewed several of these home health agencies to learn whether they were interested in providing Medicaid home health care. The agencies interviewed told us that they were interested, but due to current agency missions, philosophies or regulatory restrictions are not presently able to supply such services. They would, however, like to be considered as potential participants in discussion of alternative PAS service delivery models.

VII. CONSUMER FOCUS GROUP

Purpose
To better understand consumer perspectives and experiences with PAS and Home Health Care services in Nebraska.

Methodology
Six consumers and one personal assistant were selected[25] to participate in a consumer focus group on January 8, 2002 in Lincoln, Nebraska. The consumers are members of the Medicaid Infrastructure Grant Project Advisory Committee. The consumers shared their experiences about a variety of PAS providers and home health aides.

Sample responses are direct quotes from the focus group discussion.

Group Questions and Responses

1. **How did you find out about personal assistant services?**

Summary
Most participants found out about personal assistance through a friend or colleague. No one recalled that their caseworker suggested PAS.

Sample Responses
- I knew by the late 1970's by contact with other colleagues with disabilities
- Rehabilitation Hospital recommended a home health agency
- Through the League of Human Dignity
- From a friend and learned that Medicaid would pay for it
- Just recently on a home visit from another individual with a disability

2. **Where did you go to get approved for personal assistance?**

Summary
Much ambiguity exists about who/where to go to receive personal assistance. The League of Human Dignity, State Independent Living Councils, or other colleagues surfaced as a starting point for many who are inquiring about the service. However, access to these organizations as resources varies with geographical location across the state. It also appears to be a "who you know" type of knowledge. If you have heard about it from a friend or happen to know the right person to go to by word-of-mouth then you can get services. Otherwise, one may not even know the option is available.

Sample Responses
- In the early 1980's, I went to the League of Human Dignity to find out the process, and to go through available aides on file.

[25] During the discussion, the group mentioned that the participants at the table were "old timers" and they have had or known about personal assistance services for a long time. They also tend to be activists and more assertive than others may be. Therefore, some felt the experience of others who are less assertive, or of those who are just now trying to get personal assistance may be very different.

- In rural communities it was difficult, my father paid out of pocket for several years for local community members to provide my personal assistance. I usually went to the Kearney regional office since counties did not maintain individual offices.
- Not sure where to go, even today!
- Went to HHS staff X[26]; I knew this only because people at the League of Human Dignity told me.
- HHS staff X, and she is the only one in Lincoln that knows, your Medicaid worker doesn't know.
- State Independent Living Councils try to do outreach to hospitals or rehabilitation centers about the service of personal assistance.
- Home health agencies also do a lot of recruiting.
- Usually the consumer will go to the doctor and ask for the letter. The doctor doesn't advertise the need for a personal assistant. The consumer has to ask.

3. Is personal assistance available when you need it?

Summary

Most participants voiced, "not really." They do not feel personal assistance is available to meet their individual needs. They feel assistance should be tailored to reflect the needs of each consumer.

Sample Responses

- Home health agency comes at 9:30 p.m. for my evening check, but I would rather be out partying or something until maybe 10:30.
- Experience with home health agency has been good. They come when needed and stay as needed. But the hospital arranged it all. It was for rehab.
- A lot of people are going to bed at 8:30 on a Friday night because the home health agencies don't have someone to come out and put them to bed.
- Level of assistance you get is often a function of how many hours you need. There is an average case mix per diem; if you equal or exceed that you have to go to a nursing home.
- Depends on who you are, I get more than most, but they won't press the issue because they know I'll fight it.
- People [aides and consumers] get confused on what is considered/allowed payment for housekeeping.

***4.* Do personal assistants/home health aides provide you the services you need/want?**

Summary

There are major differences in the care received by independent contractors and home health aides. Service delivery varies with respect to availability of personnel, types of service provided, and quality of care. Consumers feel they are pretty much at the mercy of what they know to be available and it is their responsibility to figure out ways around the system to get the services they need to be independent and have choices.

Sample Responses

- There are things that the aide is not supposed to do, but they will do and just not record it as such.

[26] To protect identity, we used "HHS staff X" to replace people's names.

- The Nurse Practice Act allows certain things to be done, but home health aides will not do these because of liability issues.
- Home health aides are very restricted on what they can provide legally, but sometimes they go ahead and do it anyway for the consumer.
- With independent contractors, consumers have to set their own back up in case someone doesn't show.
- If I want to work late, I may have a problem finding someone to meet me at home to assist me to bed. The home health agency only has someone for me at 8:30 and I will be working later than that. Plus it takes me 50 minutes to get home from work when I walk.
- Can a personal assistant provide transportation too? The Handi-Van only runs from 8-5 in some parts of the state. If I want to go to a baseball game or a movie, I am stuck.

5. What do you consider a "good" personal assistant?

Summary

Participants agreed that a good personal assistant has a positive outlook and is flexible and attentive to a consumer's unique needs.

Sample Responses

- The answer is very subjective, depends on the person, it varies.
- A good assistant needs to address consumers individually.
- Abuses to the system will always be there, you can't build a system that prevents every feasible abuse. If you do, you will build a fortress around service accessibility.
- The woodwork effect, of "everyone will want this service and abuse it" is absurd. If services aren't needed people aren't going to ask. There is too much bureaucracy.
- Spend money on services, not preventing abuse
- Lack of qualified aides
- A good aide lets me do what I can for myself and provides services to meet my unique needs.
- Mainly, I just want a personal assistant with a good attitude, and the client has to have a good attitude too. Everyone needs to understand there are going to be bad days for both.
- Need to be liberated and know about the homebound language
- We need to view personal assistance as a profession. We need to be willing to pay personal assistants better wages and provide benefits so more people are willing to be aides.
- They should have the philosophy of the independent living model, not the medical model.
- The best aides are the ones that know nothing, and I train them.

6. Who do you contact when you have problems with your personal assistants?

Summary

Many consumers reported feeling reluctant to fire personal assistants either because they feel intimidated to fire, or because they fear there will not be anyone else to take the place of the fired provider.

Sample Responses

- Case manager
- Knowing what to do and doing it are two different things. Not every consumer is empowered to address problems.
- Statewide Independent Living Centers have assertiveness training to help with this.

- A lot of consumers are intimidated by their personal assistants and know that there is not much choice.
- It is a two-way street, many personal assistants need their jobs and they are being scrutinized by their consumers as well.
- There is a fear of calling and complaining to a home health agency.
- Need more support from HHS when consumers need to fire a personal assistant.
- I don't like to fire people, because I don't want to hurt their feelings.

7. **Do you feel like you have enough control over your personal assistance services? Note: Some alternatives presented were: brokerage, cash and counseling, fiscal intermediary**

Summary

Participants concurred: The current model is not working for everyone. However, the chosen alternative should include many options. Each person is unique as mentioned in other sections; therefore service delivery should meet individual expectations and needs.

Sample Responses

- There need to be choices
- One alternative may not work for all people
- Some people aren't responsible enough for cash and counseling
- There is a fine line between how much the state should legislate our own responsibilities, there is no blanket option.I advocate for cash and counseling, if you blow your money, you sit. It is no different than the responsibility others have.
- Should be an individual choice about how much responsibility one wants

VIII. SUMMARY AND RECOMMENDATIONS

Background

In this section we offer 11 recommendations, which are designed to improve the provision of PAS in Nebraska. Our recommendations focus only on the provision of PAS and do not address home health care.

Our recommendations focus on policy options at the state level and not at the federal level. We recognize that some will be easier than others to implement. We expect that several of these recommendations may potentially be cost-neutral or cost-saving, but realize that some will require additional funding. Exact financial cost projections are beyond the scope of the current research, however, we believe none of the recommendations are fiscally unobtainable.

The recommendations are based on the variety of information presented in this report. We draw from our review of federal and state policy, interviews with key HHSS employees (Central Office and local offices in each service area), a home health agency questionnaire, and a consumer focus group. Data were collected from October 2001 through February 2002. We also relied upon numerous documents and reports prepared by academic researchers, policymakers, and advocacy organizations.

The recommendations that follow are the Public Policy Center's, and they do not necessarily reflect the views of any particular person or agency, inside or outside of Nebraska. Rather these recommendations reflect our interpretations and judgments based on the input we received from all of the information we collected.

Overview: 11 Recommendations for Improving PAS Service Delivery in Nebraska

<u>Outreach and Awareness</u>

- Improve **internal communication within HHSS about PAS as a work support** by utilizing existing HHSS communication strategies such as HHSS employee newsletters, other employee communications, and listserv email messages.

- Develop and distribute **PAS informational materials for outreach beyond HHSS** through consumer service and advocacy organizations, including the League of Human Dignity and the League's Statewide Consumer Network, as well as medical centers, rehabilitation centers, community centers, advocacy groups, and educational facilities.

<u>Case Management</u>

- Develop and incorporate **PAS approval and management training** for new and existing HHSS employees into other training activities.

- Create a HHSS communications task force consisting of HHSS Central Office administrators, Long Term Care administrators, local office supervisors and case managers to develop **a communications plan that will ensure efficient dissemination of changes to the regulations**.

Recruitment and Retention of Independent Providers (Personal Assistants)

- **Investigate the feasibility of a PAS brokerage system** to organize and employ independent providers and enable the provision of fringe benefits.

- Encourage personal assistants to take advantage of **direct deposit.**

- Encourage the development of **statewide provider databases**, which could potentially be accomplished by a subcontract or broker.

- Encourage other organizations to provide **personal assistance training** for independent providers to improve quality of care and to allow additional independent providers to claim the "trained" pay rate, perhaps affecting retention.

Quality Assurance

- Develop a **standardized quality assurance process** that includes provider performance reviews. We also recommend that **quality assurance be included in PAS training.**

- **Investigate consumer-directed service delivery** models that enable consumers to develop their own definitions of quality service and a plan for participating in quality assessment.

PAS Federal/State Policy Options

- Conduct **additional policy analysis**, which would **further detail the federal parameters for the Personal Care Option along with state policy.**

OUTREACH AND AWARENESS

1. Improve Communication Within HHSS About PAS as a Work Support

We recommend improving internal communication about PAS as a work support within HHSS by utilizing existing HHSS communication strategies such as HHSS employee newsletters, other employee communications, and listserv email messages.

Across the state, our interviews with local office staff indicated that there is limited awareness of the availability of PAS as a work support.

- We learned from the interviews with HHSS employees as well as consumers that referral to PAS by case managers is seldom the most common method of referral unless done at the initial assessment for Medicaid.
- Case managers reported that they have not dealt with requests for PAS outside home settings because very few or no consumers with whom they work are engaged in competitive employment.
- We also learned that, in most cases, HHSS employees are not aware of any PAS consumers on their current caseloads who are interested in working.
- The case managers interviewed suggested that case managers may not encourage consumers to join the workforce or suggest to consumers that PAS is available as a work support.

To improve local office staff awareness of PAS as a work support, we recommend focusing communication with all local offices on information about PAS. This could be accomplished through the use of such existing communication strategies as the HHSS newsletter or listserv email. Short articles highlighting the experience of consumers using PAS as a work support could be used to increase local office awareness.

2. Develop and Distribute PAS Informational Materials for Outreach Beyond HHSS

We recommend the development and distribution of PAS informational materials through consumer service and advocacy organizations, including the League of Human Dignity and the League's Statewide Consumer Network, as well as medical centers, rehabilitation centers, community centers, advocacy groups, and educational facilities.

Discussion during the consumer focus group indicated that many consumers are not well informed about the availability of PAS as a work support.

- Participants in the consumer focus group told us that they believe most consumers do not know who to talk to or where to go to receive PAS.
- Service and advocacy organizations such as the League of Human Dignity surfaced as a starting point for PAS information and referral.

To improve consumer awareness of PAS as a work support, we recommend the development and distribution of PAS information materials to consumer advocacy and service organizations. The League of Human Dignity and the League's Statewide Consumer Network are likely good places to begin. Other potential outlets for information dissemination may include medical centers, rehabilitation centers, community centers, advocacy groups, and educational facilities.

CASE MANAGEMENT

3. **Develop and Incorporate PAS Approval and Management Training**

We recommend that HHSS develop and incorporate PAS approval and management training for new and existing HHSS employees into other training activities.

The high volume of worker caseloads reduces worker ability to focus on programs like PAS, which have relatively low enrollment. Because they do not manage PAS frequently, workers are less familiar with program characteristics.

- These case managers told us that they do not enroll consumers in the PAS program very often (especially when compared to other programs), so they are not very familiar with it.

The interviews indicated several areas of confusion about PAS program characteristics:

- There was confusion among case managers interviewed about the maximum number of PAS hours they could authorize before special "extended hour" permission is required from the Central Office.
- Many HHSS staff are unaware of the most recent exception to the PAS regulations allowing PAS to be provided in locations other than a home. Specifically the changes made to 471 NAC 15-002, allowing "*personal care to be provided at a client's worksite when the client is engaged in competitive integrative employment*" have not been

effectively communicated to case managers.
- Some HHSS employees reported that it is confusing to differentiate between PAS needs and housekeeping or chore services.

To improve case management of PAS consumers, we recommend the development and provision of PAS training for new and existing HHSS employees. We recommend that the training involve the following:

- Include information on PAS in pre-service training for new case managers;
- Include information on PAS with other documentation provided to new case managers;
- Provide in-service or some other special training for current case managers;
  - Document the efficacy of case managers' knowledge about PAS after receiving the training;
  - Review and clarify state regulations regarding the number of "approvable" hours, eligibility criteria, and the distinction between chore services and PAS; and
  - Clarify and communicate the notion that PAS exists to improve the independence of people with disabilities living in communities, and is not necessarily limited to "medical" activities.

4. Develop Communication Plan to Disseminate Regulatory and Policy Changes

We recommend the creation of a HHSS communications task force consisting of HHSS Central Office administrators, Long Term Care administrators, local office supervisors and case managers to develop a communications plan that will ensure efficient dissemination of changes to the regulations.

Across service areas, interviewees reported that there is no consistent and reliable method for case managers to receive information about changes to state regulations and policy.

- The data reflect that currently throughout the state there is no standardized process for dissemination of new rules and regulations, changes to current rules and regulations, or updating of current manuals.
- Each office interviewed has its own method of communicating pertinent information. In some locations no process existed.
- HHSS employees are very aware of the HHSS intranet as an access point for state regulations.

A HHSS communications task force consisting of Central Office administrators, Long Term Care administrators, local office supervisors and case managers should be charged with developing a communications strategy that will ensure efficient dissemination of changes to the regulations. Potential strategies for this group to consider may include the following:

- Efficient use of current intranet on-line regulations manual (should include appendices) ensuring updates are promptly made by the Central Office so case managers and other HHSS employees have an efficient, accurate and comprehensive way in which to access program regulations.
- Send email "alerts" to local office staff whenever changes to the regulations are approved.

- Develop mailing lists for communications of "hard copies" of information.
- Identify a HHS "point person," with PAS expertise, for case managers to contact in the event that questions dealing with PAS regulations arise.

RECRUITMENT AND RETENTION OF INDEPENDENT PROVIDERS (PERSONAL ASSISTANTS)

5. Investigate the Feasibility of PAS Brokerage System

We recommend the investigation of the feasibility of a brokerage system to organize and employ independent providers and enable the provision of fringe benefits.

Across the U.S., there is a growing recognition that, for people with disabilities, increased participation in competitive employment will likely involve increased reliance on PAS. An increase in the number of providers may be necessary to meet this growing need. Unfortunately, in Nebraska, current lack of employee benefits and inconsistent recruitment and coordination may serve as disincentives and discourage potential personal assistants from entering or staying in the field.

- Personal assistants do not receive any employee benefits.
- There is inconsistency across service areas with respect to how personal assistants are recruited (i.e., whose responsibility it is), and how lists of available personal assistants are created and maintained. This inconsistency has often resulted in case manager and consumer confusion, which may lead to inefficient provider recruitment and enrollment.
- Personal assistants are involved in completing and filing a large amount of paperwork for HHSS (e.g., various provider enrollment forms, Care Plans, MC-82 – payment claim forms).
- There is a presumed long lag time from when payment is requested (i.e., consumer and local office staff sign billing paperwork) and when the personal assistant actually receives payment.
- Participants in the consumer focus group were concerned about the quality of PAS that is available to meet their individual needs. They would prefer to have a larger pool of potential providers from which to choose.

We recommend the investigation of the feasibility of a brokerage system to organize and employ independent providers and enable the provision of fringe benefits. The brokerage service delivery model allows personal assistants to be part of an organization that purchases employee health care and other benefits. Brokerage systems may also utilize a provider database to increase the efficiency of consumer assignments and scheduling. Brokerage systems can improve the pool of providers, monitor geographical availability, and improve provider retention. It may be more effective to employ a single, streamlined approach to provider recruitment rather than multiple approaches.

6. Use Direct Deposit for Payroll

We recommend that HHSS encourage personal assistants to take advantage of direct deposit.

Personal assistants are responsible for completing MC-82 (payment request) forms. Every pay period, they fill out the form, have the consumer sign it, and then deliver it to the local office. At

the local office, the case manager reviews it and signs it before sending it to Central Office for payment processing. Once Central Office receives the MC-82, the average turnaround for payment is ten days. However, it is unknown exactly how long MC-82s sit at local offices before being sent to Central Office. Direct deposit would decrease the ten day time period, decreasing the amount of time required for a personal assistant to receive payment. It also saves the state time and expense in writing and mailing payroll checks. In addition, it would be useful to assess the amount of time MC-82s do sit at the local office and whether there is a speedier alternative process to reduce that time lag.

7. Develop Statewide Provider Databases

We recommend that HHSS encourage the development of a statewide provider database, which could potentially be accomplished by a subcontract or broker.

Some service delivery areas are keeping a list of providers and take primary responsibility for locating providers, but others do not. The adoption of this process statewide will increase the uniform availability of information about the program. It will also facilitate the enrollment of consumers who may not be connected with a provider. Services will not be delayed due to the time it takes to locate a suitable provider.

- Lag time between a request for an aide and placement within home health agencies surveyed was two days. The interviews with the selected HHSS employees stated that this process could be up to ten days for independent providers.
- Services may start immediately for providers who are pre-approved by HHSS. The use of a database to identify such providers can facilitate service provision for the consumer

To increase the efficiency of scheduling and to maximize the availability of personal assistants, we recommend the use of a statewide provider database. A database with proactive recruitment could streamline the HHSS process for provider enrollment as well as expedite services for the consumer. In addition to availability, the database could be used to track other information on providers such as work history or complaints.

8. Encourage Other Organizations to Provide Training for Providers

We recommend that HHSS encourage other organizations to provide personal assistance training for independent providers to improve quality of care and to allow additional independent providers to claim the "trained" pay rate, perhaps affecting retention.

There are few opportunities for personal assistants to receive specific PAS training that would increase their skill and knowledge base and allow them to claim the "trained" pay rate.

- Currently, Nebraska offers a higher pay rate for providers who can demonstrate they have completed an approved training program, however, programs are offered sparingly by various organizations throughout Nebraska.
- Consumers reported that they do not feel that there is enough "quality" PAS available to meet their individual needs.
- Many consumers want assistant services that are flexible and staff that are well-trained and multi-skilled as well as open to coaching by the consumer.

Increasing the training of personal assistants will increase their knowledge and skill levels, thus improving the services provided. In addition, personal assistants considered "trained" receive a higher wage, which may increase the attractiveness of the field.

QUALITY ASSURANCE

9. Develop a Standardized Quality Assurance Process

We recommend that HHSS develop a standardized quality assurance process that includes provider performance reviews. We also recommend that quality assurance be included in PAS training.

There are minimal uniform statewide standards to ensure quality.

- Interviews reflected an uncertainty among HHSS staff about how to measure quality service provision. Occasional home visits or a call initiated by the consumer were the main activities to measure quality reported by HHSS staff.
- While some service areas use home visits sporadically, none use them regularly to determine initial or changed consumer needs.
- No service area regularly utilizes on-site performance reviews to evaluate provider performance.
- Currently, some case managers are taking the approach that a consumer should call if there are problems. If case managers do not hear from the consumer and the consumer signs the provider payment request, then case managers assume there are no problems.

We recommend that HHSS develop a standardized quality assurance process that is used consistently across the state. Quality assurance should be included in PAS training.

10. Investigate Consumer-Directed Service Delivery Models

We recommend the investigation of consumer-directed service delivery models that enable consumers to develop their own definition of quality service and a plan for participating in quality assessment.

- Participants in the consumer focus group told us that they want service delivery to be tailored to each individual's unique needs.
- Consumers told us: "one model does not work for all."
- We also heard that many consumers are reluctant to fire personal assistants due to intimidation, fear, and/or uncertainty about locating replacements.
- Consumers reported that they feel they are "at the mercy" of who is available to provide PAS and what it is that they are willing to do.

We recommend investigating various consumer-directed models of service delivery to explore how consumer needs could be better met as a result of greater consumer involvement. These consumers feel they know what they need PAS for and they need a PAS program that allows them the flexibility to see that their needs are met. They acknowledged, however, that the level of "consumer-direction" that is appropriate for one consumer may not be appropriate for other consumers so a variety of options is optimal.

PAS FEDERAL/STATE POLICY OPTIONS

11. Conduct Additional Analysis of Federal/State Policy

We recommend additional policy analysis be conducted, which would further detail the federal parameters for the Personal Care Option along with state policy.

In order for Nebraska to maximize the potential PAS offers people with disabilities interested in participating in competitive, integrative employment, we recommend that a follow-up policy analysis be conducted, which would further detail the federal parameters for the Personal Care Option along with state policy. The present project reviewed federal and state policy, but only for its usefulness in understanding and evaluating current service delivery. The recommended analysis would build upon the present research by involving an exhaustive examination of Nebraska state regulations in comparison to the options evident in federal structure. The analysis should be framed to highlight state options that have been shown (via other states' experiences or academic studies) to improve employment opportunities for people with disabilities along with specific pathways (e.g., legislative or departmental) for change.

The present research has identified several policy issues that should be incorporated into the follow-up analysis we recommend. For example,

- Examine recent and continuing changes to federal regulations.
- Is the existing "medical necessity" terminology necessary for PAS? How could the definition of the scope of services focus more on the needs of consumers?
- Examine the possibility of eliminating the physician authorization that is currently required for PAS.
- Examine the possibility of expanding Nebraska's scope of PAS services.
- Examine the regulatory changes needed to maximize the use of home health care in employment settings.

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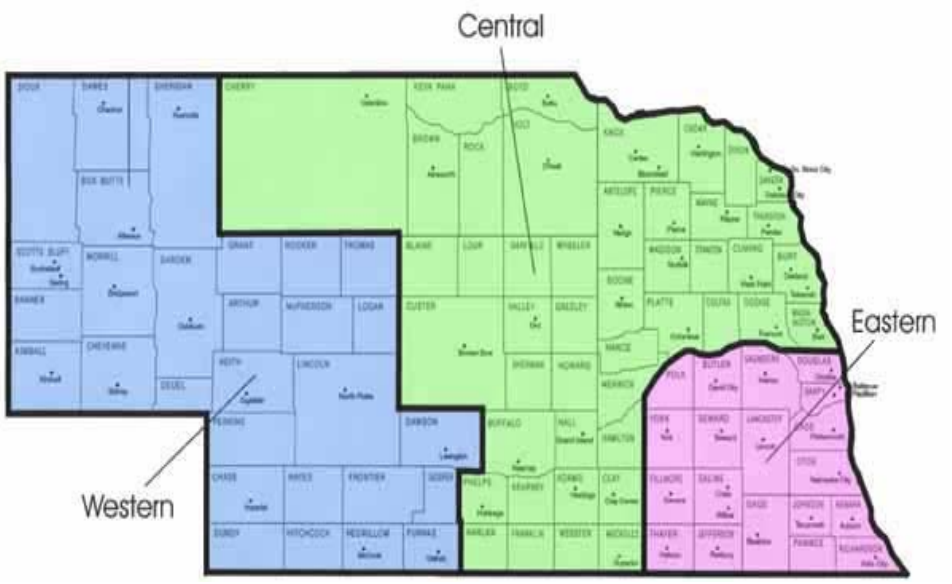
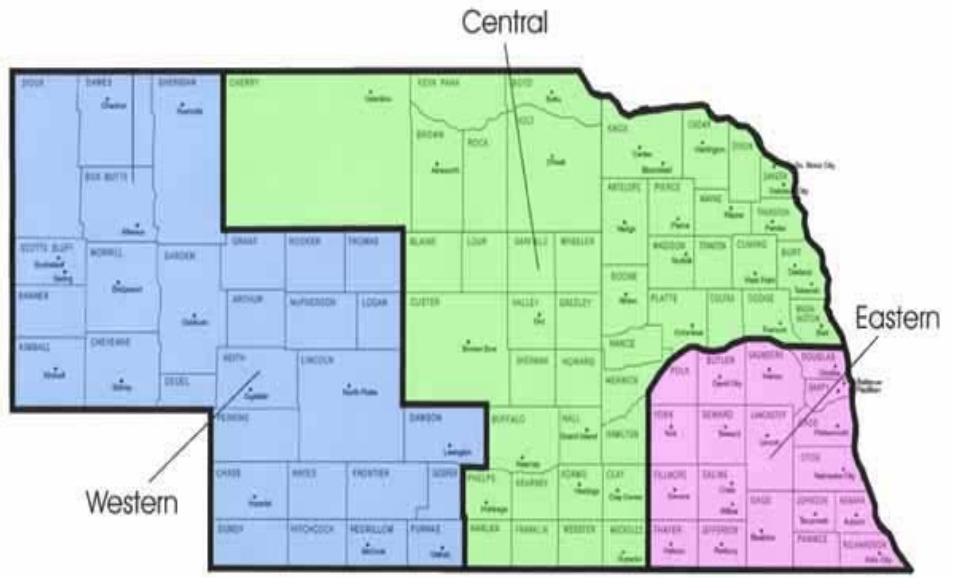
Appendix B. Map of Nebraska's HHSS Service Areas



Service Areas Prior to 2002



Service Areas 2002-present

Appendix C. Persons Receiving Personal Care Services by HHSS Service Area, FY 2000-FY 2001

	FY 2000 July 1999 – June 2000		FY 2001 July 2000 – June 2001		FY 2000 to FY 2001 Percent Change	
	Recipients	**Payments**	**Recipients**	**Payments**	**Recipients**	**Payments**
Central	277	1,029,457	253	970,094	-8.7%	-5.8%
Eastern	363	2,748,838	388	2,821,136	6.9%	2.6%
Northern	148	597,054	132	502,701	-10.8%	-15.8%
Southeast	155	759,533	206	928,959	32.9%	22.3%
Southwest	61	233,535	73	259,104	19.7%	10.9%
Western	124	584,435	131	612,295	5.6%	4.8%
Out-of-State	3	757	1	117	-66.7%	-84.5%
Totals	**1,131**	**5,953,609**	**1,184**	**6,094,406**	**4.7%**	**2.4%**

Source: HHS Finance and Support research staff

Appendix D. HHS Correspondence and Interview Guides

November 26, 2001

Long Term Care Administrator
Address
City, State Zip

Dear Long Term Care Administrator:

Subject: Nebraska's Medicaid Infrastructure Grant

Nebraska Department of Health and Human Services (HHS) received a Medicaid Infrastructure Grant from the Centers for Medicare & Medicaid Services (formally HCFA) to conduct a five-year study of Nebraska's Medicaid program serving persons with disabilities who work, or want to work, in competitive work settings. This study involves several activities, including: developing a Statewide Consumer Network, improving Nebraska's Buy-In for the Working Disabled program, improving Personal Care Aide Services in Nebraska, improving services for youth transitioning to work, and improving access to existing employment services.

As part of this research effort, the **University of Nebraska Public Policy Center** will be gathering information on **Personal Care Aide Services** in each of the six Health and Human Services System (HHSS) service areas. The Public Policy Center will be obtaining information on the number of clients served, what services are provided, client eligibility, how Personal Care Aides are paid, and quality assurance. To do this, they will be interviewing several local office supervisors and case managers in each service area. I am requesting your assistance in identifying key staff in your service area who can provide information about **Personal Care Aide Services** to researchers from the Public Policy Center. While I realize participating in this study will require a time commitment from you and your staff, I sincerely hope that we can gain your cooperation and support. In doing so, I request that you encourage your staff to take the time needed to speak with the researchers.

LaChelle Bailie or another researcher from the Public Policy Center will be contacting you within the next two weeks to request the following information:

1. The number and location of the **Local Offices** in your service area that deal with **Personal Care Aide Services**;
2. The names of and contact information for **Local Office Supervisors** who supervise Personal Care Aide

Services case managers in each local office, and;

3. The names of and contact information for **Case Managers** (i.e., front line workers) who deal with Personal Care Aide Services in each local office.

Any information you or others involved in this project share with researchers from the Public Policy Center will remain confidential and only reported to HHSS in aggregate by service area. We will not know who said what – we will only know what was said. For the success of the project, I hope that you and other HHSS employees will be candid with the Policy Center so we can get a complete and accurate picture of how Personal Care Aide Services are currently provided in Nebraska.

Thank you in advance for your time and effort on behalf of this project, and if you have any questions please feel free to contact me at (402) 471-1764, joni.thomas@hhss.state.ne.us or, LaChelle Bailie, at the University of Nebraska Public Policy Center (402) 472-1509, lbailie2@unl.edu.

Sincerely,

Joni Thomas
Medicaid Infrastructure Grant Coordinator

Questions for Local Office Supervisors

1. What are personal care services? What types of services are considered (covered under) personal care?
2. How often do workers in your office deal with cases involving personal care aide services?
    a. Approximately what percentage of your workers' full caseloads involve personal care? (What is the total caseload size?)
3. Of the personal care cases, what is the age range of those consumers who receive personal care services? (Disability types?)
4. Approximately how many of these clients are working?
5. How do consumers find out about personal care services?
6. What steps does a consumer have to follow to get approved for personal care?
    a. Who in the local office does the consumer talk to?
    b. What happens next…
    c. How long does the approval process take?
7. How does a worker determine a consumer's need for personal care services?
    a. How do workers find out if a client's needs change?
    b. What is the maximum number of hours a worker can authorize for personal care services?
    c. What is the amount of hours that is typically authorized?
8. Once a consumer is approved,
    a. How is s/he linked to a provider?
        i. Is there a list of local providers that the office can use for client referral?
        ii. How much choice do consumers have regarding who their PCA is/are?
    b. How are providers notified of the hours and services that the consumer is approved for?
    c. What other information is given to the provider by the local office?
    d. On average, how long does it take after a consumer is approved before s/he begins to receive services?
9. How are providers screened during the enrollment/application process?
10. Who submits the billings for payments to personal care aides?
11. How do you know the client is getting the services s/he needs?
12. How often and for what reasons are home visits by the HHS employees conducted? (Are they done for monitoring (quality assurance)?)
13. If a personal care aide doesn't show up, what is the client told to do?
14. Do you feel comfortable making decisions and answering consumer questions about personal care aide services?
    a. Where in the office is the regulation manual located?
    b. Who in the office is responsible for updating the regulation manual?
    c. How do workers find out about changes to the regulation manual?
    d. How and what kind of training have you received related to personal care aide services?

Questions for Front Line Workers

1. What are personal care services? What types of services are considered (covered under) personal care?
2. How often do you work with cases involving personal care aide services?
    e. Approximately what percentage of your full caseload involves personal care? (What is your caseload size?)
3. Of the personal care cases you work with, what is the age range of those consumers who receive personal care services?
4. Approximately how many of these clients are working?
5. How do consumers find out about personal care services?
    a. Do you ever recommend/suggest personal care services to consumers?
6. What steps does a consumer have to follow to get approved for personal care?
    a. Who in the local office does the consumer talk to?
    b. What happens next…
    c. How long does the approval process take?
7. How do you determine a consumer's need for personal care services?
    a. How do you know if a client's needs change?
    b. What is the maximum number of hours you can authorize for personal care services?
    c. What is the amount of hours that is typically authorized?
8. Once a consumer is approved,
    a. How is s/he linked to a provider?
        i. Is there a list of local providers that the office can use for client referral?
        ii. How much choice do consumers have regarding who their PCA is/are?
    b. How are providers notified of the hours and services that the consumer is approved for?
    c. What other information is given to the provider by the local office?
    d. On average, how long does it take after a consumer is approved before s/he begins to receive services?
9. How are providers screened during the enrollment/application process?
10. Who submits the billings for payments to personal care aides?
11. How do you know the client is getting the services they need?
12. How often and for what reasons are home visits by the HHS employees conducted? (Are they done for monitoring (quality assurance)?)
13. If a personal care aide doesn't show up, what is the client told to do?
14. Do you feel comfortable making decisions and answering consumer questions about personal care aide services?
    a. How often do you consult a co-worker or the regulation manual?
        i. Where in the office is the regulation manual located?
        ii. Who in the office is responsible for updating the regulation manual?
        iii. How do workers find out about changes to the regulation manual?
    b. How and what kind of training have you received related to personal care aide services?
15. Do you know of any clients on your caseload who receive personal care services that are interested in going to work? What kind of personal care assistance would they need at work? Is that even possible?

Consumer Focus Group Questions

1. How did you find out about personal care aide services?
2. Where did you go to get approved for personal care?
    a. Is there a specific person at HHS that you contact regularly? If yes, is this who you went to to get approved? What else do you contact him/her for?
    b. What did you have to do to get approved?
3. Is personal care available to you when you need it?
    a. Do you receive personal care services at the hours you need them most?
    b. Do you experience lapses in services? If so, how often? Why?
    c. If working, would you need a personal care aide at work?
4. Do personal care aide services provide you the personal assistance you need or want?
    a. Are there any additional services that you need? If so, what?
5. How many different personal care aides do you receive assistance from on a daily/monthly basis?
    a. If your usual PCA is sick or on vacation, do you have a "back-up" person to fill in? Do you have to arrange this?
    b. How often has your PCA quit or been fired and you have to change PCAs?
6. How many of you use personal care aides from an agency? (i.e., Home Health Aides)
    a. How many of you use personal care aides that are independent contractors?
7. What do you consider a "good" personal care aide?
    a. What do you consider "quality care"?
    b. What do you do if you have a problem with your Aide?
8. Do you feel like you have enough control over your personal care services?
    a. What kinds of decisions about your personal care do you make regularly?
    b. What kinds of decisions about your personal care do you wish you could make?
    c. Alternatives…
        i. In some states, personal care aid services are handled through a "cash and counseling" program. In this program, consumers are given money and counseling/advice and then given the responsibility to spend that money in a way that meets their service needs. Is a "cash and counseling" program something you would feel comfortable with? Why or Why not?
        ii. Another option states are trying is a "fiscal intermediary" system. In this case, consumers are responsible for managing their personal care services except for any financial aspects, like paying PCAs, filing taxes, and so on. Is a "fiscal intermediary" system something you would feel comfortable with? Why or why not?
        iii. Finally, some states have set up a "brokerage system" where an organization is set up that is responsible for linking consumers to providers – making sure that you have the services you need – while also handling all financial aspects. In this model, the organization is able to pay benefits, workman's comp, etc. – like a HMO… (??)
        iv. Would you feel comfortable with…
            1. Recruiting and hiring your PCA?
            2. Training your PCA?
            3. Paying your PCA?
            4. Firing your PCA?
9. Is there anything about the personal care services system/program that you would like to see changed? If so, why?

Appendix E. Home Health Agency Correspondence and Questionnaire

November 12, 2001

_____, Administrator
Home Health Care Agency
Address
City, State Zip

Dear Home Health Care Administrator:

Re: Nebraska's Medicaid Infrastructure Grant

The Nebraska Department of Health and Human Services (HSS) received funding from the Centers for Medicare & Medicaid Services (formally HCFA) to conduct a five-year study of Nebraska's Medicaid program serving persons with disabilities who work, or want to work, in competitive work settings. Nebraska's Medicaid Infrastructure Grant project involves several activities, including: developing a Statewide Consumer Network, improving Nebraska's Buy-In for the Working Disabled program, improving **Personal Care Services** in Nebraska (including Independent contractrs as well as Home Health Agencies), improving services for youth transitioning to work, and improving access to existing employment services.

The **University of Nebraska Public Policy Center**, through a contract with HHS, will be gathering information throughout Nebraska on topics related to the provision of **Personal Care Services**. The Public Policy Center will be looking salaries of Home Health Aides, the state's capacity for providing Personal Care Services and quality assurance.

I am requesting your assistance in answering some specific questions related to the provision of Personal Care Services via Home Health Agencies. **Please take about 20 minutes of your time to answer the questions on the enclosed questionnaire.** For your convenience, you may return the completed document in the enclosed postage-paid envelope. **We request that you please return the questionnaire by January 15, 2001.**

Any information you or others involved in this project share with researchers from the Public Policy Center will remain confidential and only be reported to HHS in aggregate by service area. We hope that you will be candid with the Policy Center researchers so we can get a complete and accurate picture of how Personal Care Services are currently provided in Nebraska.

Thank you in advance for your time and effort on behalf of this project. If you have any questions, please fell free to contact me at (402) 471-9360, nancy.olson@hhss.state.ne.us or, LaChelle Bailie at the University of Nebraska Public Policy Center at (402) 472-1509, lbailie2@unl.edu.

Sincerely,

Nancy J. Olson, RN
Unit Manager

Home Health Aide Questionnaire

Please answer the following questions regarding **Home Health Aides** paid through **Medicaid** at your agency. Once you have completed the questionnaire, please return it in the self-addressed stamped envelope. We would appreciate receiving your completed questionnaire by **January 15, 2002**.

1. How many Medicaid clients does your agency serve? _____

2. What percentage of your Medicaid served clients fall within each category below?

___% are younger than 18
___% are of working age (18-64)
___ % are elderly (65 and over)

Total should equal 100%.

3. How many Medicaid clients does your agency serve at a work site? _____

4. When are Home Health Aide services available through your agency? Please check all that apply.

____ Monday - Friday
____ Saturdays
____ Sundays
____ Holidays
____ 8 am – 5 pm (or variation on regular workday)
____ early mornings
____ evenings
____ 24 hours a day

Does this apply to your entire service delivery area?

____ Yes
____ No, please explain: _____

5. Does your agency provide "split hour" services; for example, do Aides visit a client for a few hours in the morning and then return to that same client later in the day?

____ Yes
____ No

Comments _____
_____

6. Approximately how many days does it take to fill a request for a Home Health Aide, once you have accepted a case? _____

7. What are the geographic boundaries of your service delivery area?

(*please continue on reverse side*)

8. How does your agency bill? Please check all that apply.

____ By the hour
____ By the visit (a set number of hours)

9. What is the average pay and pay range for Home Health Aides at your agency?

Average pay: $_____
Pay range: $_____

10. What benefits are available to Home Health Aides as employees of your agency? Please check all that apply.

____ Vacation pay ____ Reimbursement for transportation ____ Worker's compensation
____ Health insurance ____ Retirement accounts ____ Unemployment insurance

Comments/Other
_____
_____
_____

11. What incentive tools do you use to recruit or reward Home Health Aides at your agency?

12. What is the turnover rate for Home Health Aides at your agency? _____

13. What options does a client have if dissatisfied with a Home Health Aide from your agency?

14. What quality assurance mechanisms does your agency have in place? Please check all that apply.

____ Consumer satisfaction surveys
____ Onsite review of Aide performance based on service standards
____ Background checks on Home Health Aides
____ Other, please describe:_____
_____

15. During the last three years has your agency expanded the population that it serves (e.g., expanded service area, added age groups)?

____ Yes, please describe: _____
_____
____ No